

PALLIATIVE CARE IN NORTH KARELIA

– The best humane care
for patients

Henna Myller (ed.)



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Foreword

The Paletti project [Strengthening the Competence and Developing the Structures in Palliative and End-of-Life Care through Expert Cooperation in the Province of North Karelia] was conducted in 2013-2015. The purpose of the project was to strengthen multiprofessional cooperation and competence and to develop the structures in municipalities belonging to North Karelia Health and Social Services Consortium (PKSSK). The most essential area of development was creating an operational model for regional palliative and end-of-life care. The developed model consists of an operating model for multiprofessional networking, a regional end-of-life care plan and a portal for end-of-life care, a description and visual modelling of a good environment for end-of-life care, and a clarification of the possibilities of organising emergency care in the implementation of palliative care at homes outside city centres. The operating model also includes a basic-level study unit on palliative and end-of-life care for registered nursing and public health nursing students at Karelia University of Applied Sciences (Karelia UAS) and for practical nursing students at North Karelia Municipal Education and Training Consortium (PKKY). In addition, the model includes a post-graduate continuing education model in nursing. As a result of the project, the planning of continuing education in palliative nursing will be realised in the future in cooperation with the PKSSK, PKKY, and Karelia UAS.

Multiprofessional collaboration between several organisations was the cornerstone of this project. Representatives of social and health care organisations and specialised health care, and representatives of municipal public, private and patient organisations were involved in the development work. The project was funded by the European Social Fund through South Savo Centre for Economic Development, Transport and the Environment (ELY Centre) and the following project partners; North Karelia Health and Social Services Consortium, North Karelia Municipal Educational and Training Consortium and project administrator Karelia University of Applied Sciences.

The main approach in the project was based on the principle of patients having the right to receive good palliative and end-of-life care alleviating their symptoms regardless of

their place of residence. At the beginning of the project, the organisation of palliative and end-of-life care in North Karelia province was insufficient, the level of care was varying, and there were no unified practices for patients' clinical pathways. In addition, there was a lack of wards and treatment units with competence in and focus on end-of-life care. Care provided by different specialised health care fields at hospitals, health care centres and homes proved to be challenging. The demographic structure of the province indicates a large number of older people and as a result, different groups of diseases become chronic and more common. Consequently, the need for both primary and specialised health care expertise increases in organisations providing health care services.

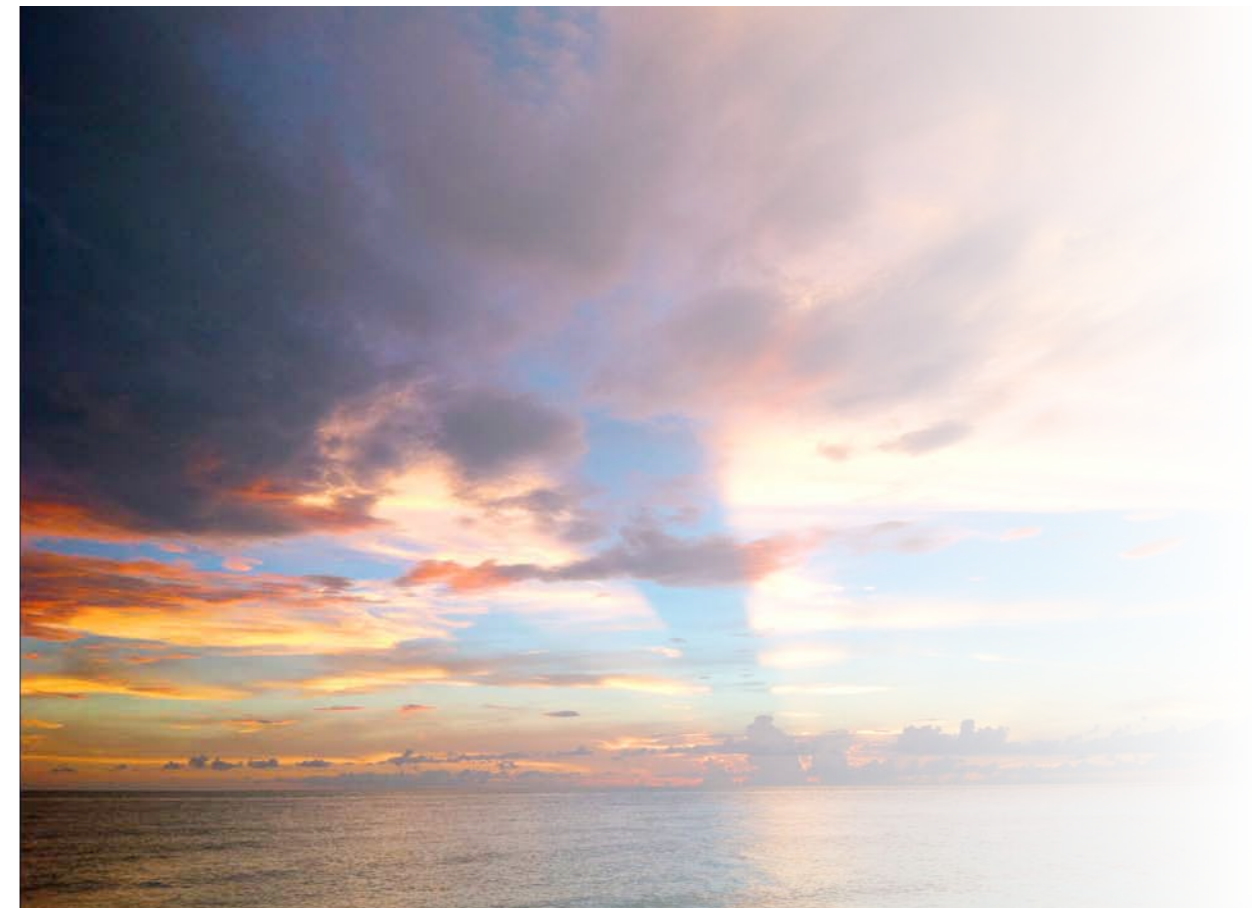
This publication describes the experiences, development work and results gained during this project from different perspectives. The articles provide an extensive, diversified picture of the development work as a whole.

A successfully implemented project requires good, goal-oriented and innovative cooperation. Here in North Karelia, we have had a strong, shared will and commitment to promote good, humane palliative and end-of-life care, which has contributed to the implementation of this project. I wish to thank all of you involved in the project for your significant development cooperation: project partners from different organisations, students, teachers, representatives of municipalities and nursing homes, members of the steering group, and other experts. I sincerely hope that development of palliative and end-of-life care and any related collaboration will continue in the future in as enthusiastic and goal-oriented manner as during the project.

I also wish to express my gratitude to each author of articles in this publication and other people contributed to the compilation of this publication.

In Joensuu 31 October 2014

Henna Myller



PALLIATIVE CARE IN NORTH KARELIA – A DECADE OF DEVELOPMENT WORK

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Palliative care has been an object of development in the province of North Karelia since 2005 through project funding from several European Structural Funds (Palliatiivisen hoidon kehittämishanke 2005-2008, Kotihoito24h 2008-2011, and Paletti 2013-15). When the first project started in 2005, the concept of palliative care was still strange to Finnish nursing staff. Moreover, it was a completely new and an unfamiliar concept to the general public. At the same time, there was lively debate on whether the term palliative care could be interpreted into Finnish in a clear and simple way. The concept of oirehoito (care of symptoms) was not enough to describe the extensive scope and context of palliative care, preventing and relieving suffering, early recognition, prevention, relief and care of pain and other physical, socio-psychological and existential problems and factors that weaken the quality of life. The term palliative care is known and used worldwide. Nowadays, the term palliatiivinen hoito (palliative care) has also become established in Finland, although saattohoito, i.e. end-of-life care (care of the terminally ill), still remains the best-known aspect of palliative care. In recent years, palliative care has not only been associated with treating cancer patients. Other patient groups that require palliative care are patients with e.g. neurological disorders, dementia, chronic obstructive pulmonary disease (COPD), chronic or progressing cardiovascular diseases, or cerebral circulatory disorders.

The first project in this field in North Karelia, called Palliative Care - Quality of Life for Incurably Ill Patients (2005-2008) was funded by the European Regional Development Fund (ERDF) through the Regional Council of North Karelia. The project was administered by Karelia University of Applied Sciences (called North Karelia University of Applied Sciences at the time). It was a cooperation project between North Karelia Health and Social Services Consortium

” When the first project started in 2005, the concept of palliative care was still strange to Finnish nursing staff. Moreover, it was a completely new and an unfamiliar concept to the general public.

(PKSSK), five municipalities and cities (Joensuu, Iloanta, Lieksa, Kitee and Heinävesi), four North Karelian nursing homes (Piritta and Tervokoti in Joensuu and Kanervikkola-koti and Eerika in Kitee) and North Karelia Cancer Association (Project proposal 2005).

The operational model throughout the project was to create a learning and development process in the form of dialogue utilising the data from the latest international and national research, expert knowledge and experience as well as experiences from the patients and their families. During the course of the project, the working communities became better aware of palliative care and the expertise in palliative care was strengthened. As a result, key concepts such as advance health care directive, decision to start end-of-life care, decision on DNR and care procedures, and the legal foundation for end-of-life care were discussed. Moreover, the question of responsibilities was clarified and the know-how on end-of-life care within the care personnel was strengthened by networking and cooperation as well as training.

During the project, nurse-to-nurse and doctor-to-doctor consultations were enhanced. Negotiations between the patient, his/her family, the doctor and the nurse started to increase and documenting the DNR decision and end-of-life care improved. The multiprofessional care team was strengthened with an addition of a registered nurse from the Cancer Association. The excursions in the project and job rotation offered the care staff increasing awareness of each other's work and they clarified the idea of opportunities and expertise in primary health care. In specialised health care, the job description of one registered nurse was changed to meet the needs of the further care and discharge of a severely ill patient. (Myller 2007)

The Palliative care project (2005-2008) developed the procedures of end-of-life care and created a patient-oriented model of end-of-life care which considers the support from the family. In addition, several operational instructions for palliative care of symptoms were produced, an ESAS symptom questionnaire was tested in the work communities and a DVD called 'Lämpimin käsin' was produced to support the patient and his/her family in grief. During the project, a regional network of registered nurses in palliative care was established. Furthermore, the project created close cooperation with the third sector and set a foundation for national networking in the field. Expert support was received from the expert organisations in palliative care of Tampere University Hospital, Helsinki University Central Hospital (HUS) and Kuopio University Hospital as well as experts in palliative care at Tervokoti nursing home and experts from the Finnish Cancer Association, the Finnish Association in Palliative Care, the Finnish Association of Registered Nurses in Oncology, and the National Institute for Health and Welfare (Stakes). Cooperation was further developed with associations and organisations, such as the Dementia Association in North Karelia (Pohjois-Karjalan Dementiayhdistys), the Association for Parkinson's Disease in Joensuu (Joensuun Parkinson-yhdistys), associations for family carers in Joensuu (Joensuun Seudun Omaishoitajat ja Läheiset ry), church parishes, and hospital chaplaincy. (Myller 2007)

In the course of the project, Karelia UAS (previously North Karelia UAS) conducted a specialisation course of 30 ECTS credits in palliative care for nursing students and a 10-credit apprenticeship training in palliative care for practical nursing students. These students have been actively contributing to the further development work and implementing the results of the project in practice.

The Kotihoito24 project (HomeCare24, Developing Round-the-Clock Home Care as a Regional Network Cooperation) was conducted in 2008-2011. The aim of the project was to develop demanding round-the-clock home care in hospital standards as an alternative to hospital care. One of the main development areas was end-of-life care. The project was implemented as multidisciplinary cooperation across provincial and organisational boundaries. The participants were eight municipalities in North Karelia, ten private nursing homes and home care enterprises in the region, three patient organisations, special health care, North Karelia Rescue Department, and North Karelia UAS (today Karelia UAS). The project was funded by the European Regional Development Fund through the Regional Council of North Karelia and the participating organisations funded the project with their self-financing shares. The project was administrated by Karelia UAS (previously North Karelia UAS). (Project proposal 2008)

The Kotihoito24 project continued to implement the good practices started in the previous palliative care project and implement them in practice in the daily work. A particular development challenge was to ensure safe evening and night care for patients in need of round-the-clock care, also for the severely ill and patients in end-of-life care. An additional aim was to support the family at home. A central objective in this project was organising home nursing services in for terminally ill patients in several of the participating municipalities. During the project, the parties in the care network created and shared common practices in home care, and refined the consultation practices and departmental support in end-of-life care in different municipalities. Intensive home care in the City of Joensuu was started at the beginning of the project in August 2008. The aim was to develop end-of-life care at home and departmental support. Target-oriented development work in home end-of-life care has continued in the city region, the number of care staff has been continuously increasing and the operations have received positive feedback and acknowledgement for comprehensive end-of-life care. Another outcome of the project was an operational model for the discharge process of patients. The aim was to name one nurse in charge of end-of-life care in each organisation and work community. (Myller 2011, Riikonen & Kouvalainen, 2011, Lähteenmäki & Kinnunen 2011)

The development work on palliative care in North Karelia has continually progressed in a target-oriented fashion for several years. In the previous projects, a firm foundation was created for the current Paletti project – Strengthening the Competence and Developing the Structures in Palliative and End-of-Life Care through Expert Cooperation in the Province of North Karelia (funded by ESF). The incentive for the development work in the Paletti project was the overall situation in palliative care in North Karelia and the need to strengthen the expertise in the field. Reasons for starting the project can be seen in the North Karelia welfare plan, national and international surveys, recommendations, reports and earlier projects. (Käypä hoito –suositus/Current Care Guidelines 2008, North Karelia Regional Council 2009, the Ministry of Social Affairs and Health 2009, 2010, 2012, WHO Definition of Palliative Care 2014.) The results of the surveys, reports, strategies and projects show the need for developing and strengthening the expertise and networks of palliative and end-of-life care across the boundaries of organisations, municipalities and sectors as well as creating common criteria and a strategy for palliative care. In addition, there is a need to organise the division of tasks and roles and to strengthen the multiprofessional know-how in order to facilitate a smooth path in high-quality end-of-life care for the patient.

At the offset of the project, the patient's palliative and end-of-life care path was fragmented and unjust in different parts of the province. There was no coordination of organising palliative care regionally and the overall structure and responsibilities in palliative and end-of-life care were lacking. There was demand for regional multiprofessional networking in holistic patient care, doctor-nurse teams and e.g. actively including physiotherapists and social workers in the care of the patient. There was desire for clear planning and target-oriented operations for the network of registered nurses created in the previous palliative care project. One of the central concerns were the expert and consultation practices in the care of acute and more challenging symptoms in the evening and night-time in different parts of the province. One of the aims was to improve the quality of care competence since there are no special departments or expert care units focused on end-of-life care. There is a large ageing population in North Karelia and certain groups of diseases are increasing and becoming chronic, which gives rise to growing demand for basic and specialist knowledge in palliative and end-of-life care in all of the organisations in health care.

 The development work on palliative care in North Karelia has continually progressed in a target-oriented fashion for several years. In the previous projects, a firm foundation was created for the current Paletti project – Strengthening the Competence and Developing the Structures in Palliative and End-of-Life Care through Expert Cooperation in the Province of North Karelia (funded by ESF).

The Paletti project (paletti = 'palette') was started on 1 April 2013 and it continues until the end of May 2015. The project is funded by the European Social Fund (ESF), and it is carried out in collaboration with Karelia UAS, North Karelia Health and Social Services Consortium, and North Karelia Municipal Education and Training Consortium. The project is administered by Karelia UAS.

A central objective in the project has been to provide a safe and humane care path by developing the structure of the care process and methods and strengthening certain aspects of expertise of the care personnel. The development work has been done in two development teams through positive, devoted and committed multiprofessional collaboration at each of the stages in the patient care between different organisations.

The time of implementation in the Paletti project has proved to be good and the project has also been deemed a nationally significant and innovative development target. The results of a query sent to the personnel of health care centres and care homes in North Karelia show the extent and importance of the demand for development. National debate on euthanasia and proper palliative and end-of-life care as

well as end-of-life care being a target for the national Yhteisvastuu fund raising campaign 2014 have all encouraged the project personnel and care operators in the province to feel that this development work is topical and it is significant for the improvement of the care of the patient and his/her family in need of palliative and end-of-life care as well as for strengthening the competence of the care staff. Moreover, the current financial situation in the municipalities and the national structural reform in the social and health care sector have set requirements for new innovative solutions (and savings) and assessment on the structures of health care as well as devising new operating models.

To support their expertise, the project personnel familiarised themselves with good practices of palliative and end-of-life care developed in the regions of Oulu, Tampere and Lappeenranta. An excursion was also made to hospices and a cancer hospital in London, and the discussions and experiences during it strengthened the idea of the right direction and the importance of the development work. They also brought up new perspectives and insight. The national and international training events have provided inspiration and examples of good practices that can be applied in the development work.

According to the objectives of the project, some of the main aims in the project have been to create the contents and operating models for regional end-of-life care, designing and simulating a portal for end-of-life portal and creating a model for a shared study module and a model for continuing education in palliative and end-of-life care between Karelia UAS and North Karelia Municipal Education and Training Consortium. An additional aim was to create an operating model for multiprofessional networking. The framework for these development targets has been completed and providing and developing content is now underway. A model environment for end-of-life care – one of the aims in the project - has been simulated at ward 1B at the Siilainen hospital. Moreover, a survey on end-of-life care in the home care for palliative care patients outside city centres has been completed, based on which the design of the protocol of symptomatic treatment of end-of-life care patients has been started. This and the consultation practices in pain treatment will be piloted before the end of the project. The results of the project are described in more detail later in the publication. During the course of the project, the inhabitants of the province and the operators and experts in social and health care have been heard.

This gave valuable customer-oriented information for the development work. In addition, the results have been shared with the communities and organisations.

During these several projects, integration between project work and teaching has been identified as a natural part of the development of social and health care students' professional expertise and supporting their professional growth. Practical training periods, clarifications, Bachelor's and Master's theses from universities of applied sciences, development work, and Master's theses from universities conducted for the projects have contributed to the development work and to the implementation of the results in practice.

As a result of the project, Karelia UAS implemented a 30-credit (ECTS) course of specialising studies in palliative care in 2011-2012 as well as 30-credit apprenticeship studies in palliative care in collaboration with Turku University of Applied Sciences and Satakunta University of Applied Sciences. Karelia UAS has also paid special attention to enabling the strengthening of the social and health care students' competence in palliative care. The new curriculum introduced in autumn semester 2014 includes not only basic studies in palliative care, but also 15 credits of optional studies on the subject. Other studies in health care and social services also include some topics of palliative and end-of-life care.

According to the continuous education model designed in the Paletti project, the planning and development of education will continue as a cooperation between Karelia UAS and the appointed operators from the North Karelia Health and Social Services Consortium and North Karelia Municipal Education and Training Consortium. A representative of Karelia UAS is currently planning an international seminar in palliative care for 2016 in collaboration with the Finnish Nurses Association, the Finnish Association in Palliative Care and the Finnish Association of Registered Nurses in Oncology. The operators of Karelia UAS are actively following the progress of planning implementation models for specialising studies in higher education. In this aspect, one of the alternative solutions at Karelia UAS is specialisation training in palliative care.

Intensive development of palliative care continues in the North Karelia Health and Social Services Consortium. Planning and simulation of the service chain in palliative care will be simulated on the stages of care, division of tasks between units and referral and consultation practices. In addition, a Palliative Care Unit will start its operation in spring 2015 as a unit for specialised health care at North Karelia Central Hospital.

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REGIONAL STRUCTURE AND
ORGANISATIONAL CARE SYSTEM OF
PALLIATIVE AND END-OF-LIFE CARE
IN NORTH KARELIA



REGIONAL PLAN FOR PALLIATIVE CARE AND A PORTAL FOR END-OF-LIFE CARE

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NEED FOR REGIONAL DEVELOPMENT WORK IN PALLIATIVE AND END-OF-LIFE CARE

The Paletti project (Strengthening the Competence and Developing the Structures in Palliative and End-of-Life Care through Expert Cooperation in the Province of North Karelia 1.4.2013-31.3.2015) launched in 2013 has the following two aims: 1) to plan and implement a regional plan for end-of-life care in North Karelia province and 2) to set up a portal for end-of-life care to be included in the database of the North Karelia Health and Social Services Consortium (PKSSK).

In order to get a clear view of the current state of palliative and end-of-life care in North Karelia, a questionnaire was sent to all regional health care centres and the different clinic groups in specialised health care. The purpose of the questionnaire was to examine the problems and development needs in each unit before compiling a regional palliative and end-of-life care plan. Desire to develop palliative and end-of-life care was clearly expressed in questionnaire replies. Regional variation in the resources and in the level of competence as well as the lack of uniform palliative care guidelines were seen as challenges by the responding professionals.

A portal for end-of-life care planned by the project was considered necessary as an aid in accessing information and sharing experiences. The use of such a portal could improve the process of creating uniform regional end-of-life care practices. This was considered particularly important in nursing homes that do not necessarily have an access to databases used by hospitals and health care centres.

After finding out the existence of these challenges, it seemed appropriate to start clarifying different ways to organise palliative and end-of-life care for patients in North Karelia, using the existing opportunities and resources. This has been the purpose of the Paletti project: to provide regional actors an opportunity for this.

“ A portal for end-of-life care planned by the project was considered necessary as an aid in accessing information and sharing experiences. The use of such a portal could improve the process of creating uniform regional end-of-life care practices.

NATIONAL GUIDELINES AS A BASIS FOR THE REGIONAL PLAN AND PORTAL FOR END-OF-LIFE CARE

Guidelines drawn up by the Finnish Ministry of Social Affairs and Health in 2010, “Good End-of-Life Care in Finland”, states that “Good palliative care is the right of all people, which is focused on the symptomatic treatment of a dying person and on the alleviation of suffering, regardless of the diagnosis.” This publication brings up the concern about the varying quality of end-of-life care and about unequal access to care in different parts of Finland. Moreover, it was stated in the report that not all hospital districts have a regional end-of-life care plan. The purpose of the guidelines is to promote good and equal end-of-life care.

“ Patients’ end-of-life care pathway in North Karelia needs to be clarified in a way that all health care units know their own areas of responsibility both in specialised and primary health care. On the other hand, the plan underlines the importance of collaboration between different health care units.

The rise of life expectancy, increase in the number of older people, and limited health care resources present challenges to the organisation of high-quality health care. Having limited finances within municipalities and ongoing budget cuts, it might feel challenging to start organising development works of care processes and new ways of working. However, even earlier studies have found out that well-organised palliative and end-of-life care can result in savings in health care costs. Well-prepared plans for the care and clear guidelines reduce the number of patients’ emergency visits and the use of specialised health care, and at the same time increase patients’ satisfaction with their treatment. Rationally planned and implemented palliative and end-of-life care is cost effective and can even reduce costs in health care as patients are directed to appropriate units at the right time.

PLAN FOR PALLIATIVE AND END-OF-LIFE CARE

Before the Paletti project, there was no existing regional palliative care plan in North Karelia. Consequently, drawing up one became one of the key objectives of the project. This process was based on the above-mentioned guidelines by the Finnish Ministry of Social Affairs and Health from

year 2010 and criteria defined by the European Union and the European Association for Palliative Care (EAPC) in 2009 and 2010. The aim of the plan was to increase the appreciation and importance of end-of-life care as part of a patient’s palliative care process, to clarify regional clinical pathways of end-of-life care patients, to obtain information on the resourcing of regional end-of-life care and training needs, to improve multiprofessional collaboration and networking of those involved in the care of patients in end-of-life care, and to improve the involvement of the patient’s family members.

The end-of-life care plan (PKSSK 2014) describes the most relevant steps in a patient’s clinical pathway, such as transition to end-of-life care, discussion on the treatment, decision making regarding end-of-life care, end-of-life care plan, choice of care facilities, cooperation between different health care units, and support for family members and loved ones. The plan also takes into account regulations directing end-of-life care, the personnel structure and training of employees, different environments for end-of-life care, and how to support staff.

Patients’ end-of-life care pathway in North Karelia needs to be clarified in a way that all health care units know their own areas of responsibility both in specialised and primary health care. On the other hand, the plan underlines the importance of collaboration between different health care units. Smooth transfer of care responsibility between different units is essential for the patient in order to ensure the continuity of care. Particular importance has been laid on collaboration between primary and specialised health care and on the improvement of this collaboration, and as a result a regional palliative care network was set up. A doctor-nurse pair was appointed from each unit to coordinate palliative care and to be responsible for the development of end-of-life care in their own units. The purpose of this networking concept is to develop the cooperation and in addition, improve the competence and expertise in palliative care. The plan for end-of-life care will be updated and evaluated on a regular basis to meet the needs and aims of palliative and end-of-life care.

In addition to the plan for end-of-life care, arrangements regarding palliative and end-of-life care in North Karelia have now been explored more closely based on a three-step model recommended by the Ministry of Social Affairs and Health (2010). Currently, PKSSK is planning to set up a palliative care unit during year 2015. The unit will provide advanced level care and education and its purpose is also to act as a consulting unit for the most challenging issues of symptomatic care.

PORTAL FOR END-OF-LIFE CARE

The establishment of a portal for end-of-life care has proved challenging. For technical reasons, the initial goals set at the beginning of the project needed to be edited. Originally, the idea was to create a portal consisting of two parts: an open section for all those interested in palliative care and another section requiring login aimed at health care professionals. In practice, this division was not possible, especially due to security-related restrictions. In addition, problems arose around issues such as maintenance of passwords and user data after the ending of the project. Taking these things into consideration, it was decided that the portal will be a database open to all, available on PKSSK website.

The contents of the portal have been built up based on requests suggested by regional health care professionals. The purpose of the portal is to unify the different practices of end-of-life care in North Karelia and to make regional information more accessible. The portal is a common databank to be used by patients, their family members and health care professionals. In the future, the portal will be updated by the staff in the palliative care unit, members of the regional cooperation network, and palliative care students at Karelia University of Applied Sciences.


SUMMARY

The objective of creating a regional plan for palliative and end-of-life care and the establishment of a portal for end-of-life care has been clarifying the clinical pathway of patients in end-of-life care, unifying regional care practices, and improving the appreciation of palliative and end-of-life care in North Karelia, all based on the guidelines by the Ministry of Social Affairs and Health. We believe that the Paletti project has been able to give a good contribution to this work. It has been a pleasure to discover people’s understanding of the importance of palliative care in the entire North Karelia region, among all groups of health care professionals. We believe that the development work will also continue after the ending of the project due to the favourable framework that has now been created for the work. The basic idea of the development work can be encapsulated in the words of Archiatre Risto Pelkonen from year 2004: “Treatment of a dying patient is the touchstone of both humanity and medical skills, and it is the most important indicator of the quality of care in each treatment unit.”

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DEVELOPMENT OF CONSULTATION PRACTICES IN PALLIATIVE CARE



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NEED FOR THE DEVELOPMENT OF CONSULTATION PRACTICES IN PALLIATIVE CARE

The Finnish Ministry of Social Affairs and Health (2010) has pointed out in its publication 'Hyvä saattohoito Suomessa' (Good End-of-Life Care in Finland) that all health care professionals have the responsibility for the care of a dying patient and that all medical doctors need to master the principles of palliative care.

A survey conducted by the Paletti project in summer 2013 aimed at both primary health care and specialised health care showed that there is considerable variation in the competence and availability of palliative and end-of-life care. In addition, feedback received from both doctors and nurses showed, for example, that round-the-clock home care was only available in a small part of the province and there were huge differences in the resources allocated for home care. Moreover, it was discovered that most health care centres did not have a doctor on call around the clock and that the lack of clearly defined palliative care plans resulted in inconveniences in organising and planning follow-up care. Particular topics of concern also included problems related to pain management and the need for training. Another problematic aspect includes long distances in the province.

Many health care professionals working in primary health care expressed their desire for medical and professional support, which would allow the necessary consultation support all times needed, particularly concerning pain management. It was highlighted by the respondents that the patient's best should always be considered; transferring a patient on an ambulance to an emergency department far away only for getting consultation was seen hard and burdening for the patient.

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DEVELOPMENT OF CONSULTATION PRACTICES

To solve the key problems of consultation practices, a coordinating nurse in the project and an expert doctor visited specialised medical clinic groups and primary health care units. The discussions within these groups and units particularly highlighted the importance of clearly written palliative care plan for the patient. A clearly defined care plan is of great importance when the responsibility for the patient's care is being transferred from specialised health care to primary health care. Similarly, the lack of documented care plan is seen as an obstacle to further planning of care and it may cause unnecessary patient visits to the emergency department.

As a result of these visits, a designated doctor-nurse pair (from both primary and specialised health care) are to be responsible for the implementation and further development of palliative care. Other essential factors affecting the flow of information were also discovered during the visits. For example, due to the computer programming issues the information about the patient was addressed to wrong home care department that it was aimed for. As a consequence, the transfer of responsibility for the patient's care was hindered or at least delayed.

During the provincial tour it was also discovered that the municipalities do have the equipment for video-mediated consultations, if these types of practices were to be developed further. The advantage of video consultation is the possibility to avoid travelling possibly hundreds of kilometres to see the doctor. Consequently, the patient would not be forced to travel, which would also result in cost savings. The aim is to pilot video-mediated consulting services before the end of the project.

In addition, the development of good consultation practices was also considered important for nursing homes. This is particularly significant when there is a lack of medical resources and doctor's appointments are only available e.g. weekly or a few times a month. An easy consultation connection and pre-agreed practices with e.g. the municipal health care centre could facilitate problematic everyday situations, also in nursing homes. Many nursing homes have, indeed, provided us with feedback on their willingness to continue taking care of patients who have been residing in their nursing homes maybe for years, enabling the patient to be in a familiar environment with familiar caregivers until the end of his/her life. Clear consultation practices can also help nursing homes implement patients' wishes of palliative and end-of-life care.

” The advantage of video consultation is the possibility to avoid travelling possibly hundreds of kilometres to see the doctor.

The process of defining the service chain for patients in palliative and end-of-life care also plays an important role in the development of consultation practices. When certain practices are agreed on in advance and each health care unit (both in primary health care and specialised health care) is aware of its own role in the care of a palliative care patient, it is easier for the patient and his/her family and the health care professionals to work together. When writing this article, these consultation practices and the patient's service chain are under preparation with North Karelia Health and Social Services Consortium.

CONCLUSION

Due to pre-agreed division of responsibilities, uniform guidelines and practices, and a defined service chain, the patients are always aware of who takes care of them and who is responsible for the care at any given time. The aim is to lower the threshold for the communication between different health care units: to support cooperation, improve the flow of information, and facilitate consultation. Continuous training of palliative care and any related issues both in primary and specialised health care units improves the competence and understanding of the importance of good communication.

One of the duties of specialised health care is to make clear and easy to understand decisions about palliative and end-of-life care, and also record them clearly into patients medical notes. An essential part of this process includes discussions with the patient and his/her family members (if requested by the patient). Agreement on further care and smooth transfer of care responsibility between different units makes the process easier for both professionals and patients.

On the other hand, primary health care needs to take responsibility for the patient's treatment (if it can be implemented by primary health care), guarantee the patient the care s/he needs, arrange end-of-life care either at home or hospital ward, depending on the situation, and also defining care guidelines, when needed.

The process of creating good consultation practices aims at good multiprofessional cooperation in a way best suitable for the patient in palliative and end-of-life care. Organising the treatment according to the guidelines by the Ministry of Social Affairs and Health (2010) clarifies questions on responsibility and also facilitates flexible consultation in problematic situations.

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MAKING AND BROACHING A DECISION ON END-OF-LIFE CARE

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INTRODUCTION

This article is based on our thesis which was commissioned by the project Paletti project (Strengthening the Competence and Developing the Structures in Palliative and End-of-Life Care through Expert Cooperation in the Province of North Karelia in 2013-2015).

The aim of the thesis was to study the phenomenon related to making and broaching decisions on end-of-life care within the operating area of the Paletti project. The goal was to get information on how decisions on end-of-life are made and how are they broached. The aim was also to describe the problems and challenges related to making decisions on end-of-life care.

The study was conducted as a qualitative study. The collection of data was carried out by semi-structured interviews in March 2014. The target group included two medical doctors and three registered nurses within the operating area of the Paletti project. All interviewees had extensive experience of matters related to end-of-life care. The analysis of the data was performed with a content analysis using thematic categorisation.

It was found out in the interviews that decisions on end-of-life care are rarely recorded. The biggest problem in making the decisions was the high turnover of the nursing staff and the lack of courage in making decisions on end-of-life care. Facing death and a terminally ill patient was also described challenging. Talking about making a decision on end-of-life care was considered difficult. These conversations were strongly associated with the preparedness of both the patient and the nursing staff to talk about death and to accept death as a natural part of life cycle

DEFINING THE POLICY FOR CARE AT THE FINAL PHASES OF LIFE

The decision on end-of-life care is one which should be carefully recorded in the patient's medical record. (Käypä hoito-suositus 2012; Sosiaali- ja terveystieteiden ministeriö 2010, 11, 14). Careful recording of the care decision facilitates the proper care of the patient. With the written care policy all who participate in the patient's care have access to instructions of the treatment procedures concerning that patient. This ensures passing information to all involved in the care and the patient gets appropriate treatment without the risk of over- or under-treatment. (Puolakka, Aukee, Eskola, Hannonen, Jokiranta, Karjalainen, Keikkala, Korhonen, Miettinen, Nyman, Repo & Vanhala 2008, 11-12.) (Puolakka, Aukee, Eskola, Hannonen, Jokiranta, Karjalainen, Keikkala, Korhonen, Miettinen, Nyman, Repo & Vanhala 2008, 11-12.)

After the discussions about end-of-life care, the decision on moving into end-of-life care is usually made by the doctor together with the patient and his/her family members and the staff involved in the care. Ideally, this decision would be made in consensus by all participants. End-of-life care is started at the stage when life expectancy is short or the patient is not getting better regardless of active care. In addition, the patient's refusal of treatment to cure a serious disease will lead into starting end-of-life care. (Poukka et. al. 2012, 452.) The patient must get enough information about his/her health in order to be able to make any decisions about the treatments s/he wishes to have. The patient should be aware of his/her disease, its prognosis and possible treatments. S/he should also get information about the consequences of not accepting the offered treatments. (Laakkonen 2005, 50.)

” The existence of an advance health care directive facilitates the nursing staff’s decision-making about the care policy as well as the practical issues related to the patient’s care.

With the decision on end-of-life care, the role of a registered nurse as the patient’s and his/her family’s support is emphasised. Furthermore, the nurse’s part in palliative care, its implementation and evaluation, is significant at the stage of end-of-life care. (Hänninen & Anttonen 2008, 23–37.) The nurse’s role as the spokesperson for the patient’s rights can come up more clearly if the patient has differing opinions about the care with his/her family members. In this case, the nurse who is defending the patient’s will can end up in a conflicting situation. The nurse can also express his/her view and the view of the patient on the care to the doctor, especially if the views are conflicting with the intended care. (Mikkola 2006, 150–151.) Moving into end-of-life care should be aimed at providing relief from distressing symptoms and ensuring the best possible quality of the remaining lifetime (Hänninen 2012, 14–15; Heikkinen, Kannel & Latvala 2004, 55).

It would be wise to write down a statement about life supporting treatments, such as intravenous fluid or nutrition therapy, dialysis and mechanical ventilation. In addition, cardiac pace-making and DNR decision (do not resuscitate) must be dealt with in the decision on end-of-life care and recorded appropriately. (Valtakunnallisen terveydenhuollon eettinen neuvottelukunta 2008, 13.)

An advance health care directive (a living will) is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make

decisions for themselves because of, for example, unconsciousness. The advance health care directive can also be expressed verbally, in which case it should be written on the medical record of the patient and aim at verifying the directive either with a signature or some other method. (Halila & Mustajoki 2012.)

The existence of an advance health care directive facilitates the nursing staff’s decision-making about the care policy as well as the practical issues related to the patient’s care. An advance health care directive made by the patient can also relieve the psychological burden of the family when the will of the patient is known to all and the decision about the care policy is not made by the family. (Poukka ym. 2012, 452.)

CONSIDERATION OF THE RESULTS OF THE STUDY

Based on the results of the study, it can be noticed that end-of-life care in itself is a familiar concept and it is implemented in order to achieve a good final stage of life for the patient. However, decision-making and broaching the subject involve a lot of challenges and problems. Lack of decisions can, according to experiences, be an obstacle for the good fulfilment of end-of-life care.

The terms end-of-life care and decision on end-of-life care are not, according to our thesis, generally in use and decisions on end-of-life care are not frequently made. According to Mustonen (2011, 26) only two per cent of the deceased patients at Hyvinkää Hospital inpatient ward had a decision on end-of-life care made. A DNR decision was written with two thirds whereas a little less than a quarter of the patients had no recorded care policy. Issues related to end-of-life care are still talked about as terminal treatment and the DNR decision is often equated with terminal, i.e. end-of-life care. Lehto, Mustonen, Vinkanharju and Pessa (2011, 3047) see this as a problematic factor which makes targeting the care more difficult.

”Often it’s so that the term decision on end-of-life care isn’t used. In practice, end-of-life care will just be started and the procedures are fitted accordingly.” (Doctor)

According to our thesis, the number of advance health care directives was also considered small compared to their usefulness. The existence of an advance health care directive as the support for making the decision on end-of-life care was seen as significant, for the patient is often incapable of expressing his/her own will when end-of-life care is started. In the interviews, the small amount of advance health care directives was seen resulting from the lack of knowledge. The patient and the family members often do not know what is meant by the advance health care directive and the receptions do not necessarily have time or readiness to explain the matter. Patient material which could be given to the patient and the family to go through at home would be useful as a support when broaching the matter.

”There are very few of them. I’d wish it to be more so that people would prepare for what’s coming.” (Doctor)

”And there will be a note that a directive has been compiled. And then it will be a tool which can help, if there is a situation when the patient can no longer tell it him/herself and the family would like things done differently. It would be kind of an authorisation for the doctor that the patient has wished to be treated like this.” (Nurse)

The decision on end-of-life care was considered as making a policy for care for the final stage of the patient’s life. The interviews revealed various views on care policy at the stage where there are no healing treatments available for the patient. The policy was described as refraining from various nursing procedures and examinations as well as specifying alleviating care procedures.

”So that there will no longer be the kind of intensive care which causes pain or extra suffering.” (Nurse)

The challenge in making the care policy was the difficulty of specifying which treatment is for the good of the patient and which could be stopped without increasing the patient’s suffering.

”These are complex things, as there are so many diseases and even more treatments for each disease, so which are then going to be stopped.” (Doctor)

It became evident in the interviews that there are often unnecessary treatment procedures and examinations, because decisions about the care policy have not been made due to the lack of time or courage. The predictability of illnesses and the combination of many diseases with patients cause many major challenges in making the care policy and the possible decision on end-of-life care.

”...the predictability of some diseases is not good...It must be the biggest problem, not being able to make predictions. One should have a fortune-teller with a crystal ball as an assistant.” (Doctor)

Hinkka’s research (2001, 74) reveals the same factors. A patient with advanced dementia is treated more actively than a cancer patient at the end of his/her life irrespective of the doctor’s field of expertise, age or any other factor.

There are many challenges involved in the making of a decision on end-of-life care. The decision itself is a purely medical one, made by a doctor in mutual understanding with the patient and his/her family. The decision cannot be made unless there is time to get to know the patient and his/her situation. The decision-making is made more difficult by the fact that often the patient does not have a steady care relationship, but s/he is treated by a different doctor each time. Likewise, the turnover of other staff, such as registered nurses, will complicate the familiarisation with the patient’s situation and there is a possibility that no one can even notice that it would be the time to start thinking about the patient’s care at the final stage of his/her life. The turnover of doctors and nurses and the lack of resources can cause no one being willing to take the responsibility of the decision-making, but it is knowingly transferred to someone else to be considered. The obtained answers were in line with the results of a study by Laakkonen (2005, 77). Often there are several doctors and registered nurses involved in the patient’s care, so building up a good and confidential care relationship is challenging.

"Then it's successful, the kind of sliding transition that the same doctor and the same nurses are involved in the care every day. But if there are three doctors every week at the same ward, it's rather difficult. I don't think it will work very well that way. There should be a familiar nurse and a familiar patient, then it will work. This decision on end-of-life care, you can't make it in an hour. It may take a week. So it's a gradual change to the stage of end-of-life care." (Doctor)

Our thesis shows that facing death is never easy and the fear of death may be an obstacle in making decisions about the final stages in life. Doctors, just like registered nurses, aim at promoting health and curing diseases, hence the patient's upcoming death is a hard topic to deal with. According to the interviewees, an obstacle can also be that you do not want to take away hope from the patient and his/her family and new examinations and various treatments are performed even though it is known that they are of no use to the patient. Dobrina, Tenze and Palese (2014, 79) have studied that one of the most important tasks of a registered nurse who works with dying patients and their families is creating realistic hope. Then the patient and the family may have the opportunity to concentrate on accepting the incurable disease.

"Facing death is such a difficult thing." (Nurse)

"People think that they are, in a way, taken away the hope, the kind of hope that even though you know as a nurse or a doctor that the patient is not going to get well, but how important it is for the family." (Nurse)

On the other hand, the doctor may also have hopes about some treatments still working with the patient, so new examinations are still arranged just in case. The lack of knowledge about making a decision on end-of-life care as well as the lack of general policies were also considered a possible obstacle for making decisions. According to Hinkka (2001, 73-74), the physicians participating in palliative and end-of-life care training experienced less stress, even though it did not have an effect on making the decisions.

The decision on end-of-life care was experienced as meaningful for the patient and his/her family. Making the decision gives the patient the rights of a dying person and time to prepare for the coming. The experience was that both the patient and the family became more at ease with the knowledge that nothing can be done to cure the disease. Instead, the patient and the family can be explained what can be done to make the patient feel more comfortable and to support him/her in preparing for the coming death. The nursing staff also felt that the decision had a liberating effect on facing the dying patient and his/her family.

"...the dying gets such rights so that in a way he has the right to die and face his own suffering. And in a way grieve for that, and the decision does not affect, well of course it affects the dying person, but it involves then tightly all of them, relatives, family and friends. Each have a different group of close people." (Nurse)

"After that, the encounter was also much easier with these people, I mean facing the patient and his family was much easier for all of us." (Nurse)

Bringing up the decision on end-of-life care was considered important at as early stage as possible when the patient's disease can no longer be cured or treated. Then there would be time to discuss the matter many times and to define the care policy before making the actual decision. Our thesis shows that usually the matter is not brought up early enough, in which case there might not be enough time to make the decision before the patient's death. Even though the decision on end-of-life care is made by the doctor, it can be broached by any other person involved in the patient's care who thinks the time is right. Because the doctor meets the patient infrequently, the nursing staff has a major role in communication between the patient, the family and the doctor. The registered nurse can prepare the patient and the family to think about the situation even before meeting the doctor, which makes the situation easier for all parties. Because registered nurses have a big responsibility for monitoring the patient's condition and pass on information to the doctors, they are expected to have the courage to bring forward their remarks, which could increase the making of decisions on end-of-life care.

In making end-of-life care decisions, as well as in broaching them, fluent cooperation between doctors and registered nurses was seen as an important factor.

"...though I said that the doctor is the one who finally makes the decision and it's a medical decision, but we also deal with these same kind of issues in talking at home with the patient and the family." (Nurse)

"...we are really acting as interpreters between the doctor and the patient and the home." (Nurse)

According to the interviewees, broaching the decision on end-of-life care is greatly influenced by how ready the patient and the nursing staff are to talk about death and to accept the situation there are in. It may be difficult to accept the situation from the patient's and his/her family's point of view and not everyone will be in a situation that they can accept the approaching death as part of life. The patient may well refuse to talk about it and it is the patient's full right. In that case, it is difficult to make decisions. Lipponen (2006, 125, 134) also presents the fact that the patient's readiness to discuss the matter has an effect on the care relationship. Refusal to talk can cause confusion and even decrease in care activities. On the other hand, the patient and the family may have an understanding of the situation and the wish to proceed to end-of-life care comes from their side. In that case, the patient's care policy is easy to make, as well as the decision of starting end-of-life care.

"So that it's very much on a personal level... You get the sense where you are in the process of accepting the disease, close to death, if that's so, in the acceptance process of death..." (Nurse)

The ability of the nursing staff to talk about death and to accept death as part of life were seen as qualities related to age and experience. It came up in the interviews that the interviewees themselves felt that they had got more capacities as their career advanced. This was not, of course, generalised, but it was stated that some person may already have the abilities and that some other person may never get there, even after a long career. Facing death was not experienced as an easy thing, but it was felt that this matter is much easier to accept when you age yourself. Lipponen's study (2006,

145) reveals the relevance of age and maturity in a nurse's ability to face dying patients. Talking about death can be challenging, since the matter is so final. Death can also be a frightening concept, in which case also the nursing staff will not have the courage to talk about it, at least using the word 'death'.

"...it requires experience and nerve to take it up. In a way, if it's a younger, less experienced doctor, well it's a tough, challenging place. Let's put it so." (Nurse)

"One has already learnt to formulate the word or what to say so that the family also thinks that this is the way to do it." (Doctor)

"...age matters, there are young employees, surely death is not so familiar to them. It's somewhere far in the future, but when people become older, these older nurses can talk about it more openly." (Nurse)

UTILISING THE STUDY AND TOPICS FOR FURTHER STUDY

The purpose of this research was to study the phenomenon related to making and broaching decisions on end-of-life care. On the basis of the results, the project gets information about the matters the nursing staff sees as challenges and good practices when talking about decisions on end-of-life care and about broaching it.

The results of the thesis reveal the need for the information and the variety of practices. This supports the purpose of the project of composing uniform instructions for palliative and end-of-life care.

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EXPERIENCES AND FUTURE CHALLENGES OF PALLIATIVE CARE IN THE PULMONARY DISEASES CLINIC

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Pulmonary diseases clinics often treat patients with chronic diseases leading to death. Examples of such common diseases requiring palliative care include the chronic obstructive pulmonary disease (COPD), lung cancer and neurological diseases leading to respiratory insufficiency, such as the amyotrophic lateral sclerosis (ALS). At the final stage, these diseases can cause patients and their families plenty of anxiety and uncertainty in addition to the direct symptoms of the disease. Adequate pain management and treatment of dyspnoea is part of the good care of a patient facing death as well as consideration for the patient's situation of life and his/her family members.

FROM CURATIVE TREATMENT TO PALLIATIVE CARE - A DIFFICULT BUT IMPORTANT DECISION

The key objectives of the treatment of chronic diseases include improving the quality of life by eliminating or alleviating symptoms and extending the life expectancy. As the disease progresses, however, it is inevitable that the expected life of a patient becomes limited and the patient will die, as there is no curative treatment available for the disease. Then it is time to transfer the patient to palliative care, which means alleviating treatment for the symptoms, and beginning with end-of-life care. At this point, the patient, and his/her family members if requested by the patient, will have a discussion on the prognosis of the disease. The main principles of the care must be agreed on with the patient and his/her family.

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Our goal is to rely more on intensified home care in the future, if the service is available in the patient's home municipality. End-of-life care provided at home can be considered a new opportunity in the North Karelia region. This presumes a focus on multidisciplinary cooperation and taking the patient's family members better into consideration.

EXPERIENCES FROM THE PULMONARY DISEASES CLINIC

Chemotherapy given to patients with advanced lung cancer can also be considered palliative care, since it improves the patient's prognosis and quality of life, but hardly ever cures the lung cancer itself. The life expectancy is extended by a couple of months, sometimes even longer. The most important thing is to prevent the side effects of chemotherapy, particularly nausea. Lung cancer progresses typically slowly at first, which allows the patient to maintain his/her independence and to be able to stay at home for a long time. Then again, the final step of the disease progresses quite fast. Consequently, hospitalisation may not be required until the final stage of the disease, which is why it is not unusual that the patient has only been at the hospital for only a few days before his/her death.

The end-of-life care of a lung cancer patient at the pulmonary diseases clinic consist mainly of pain management during the final stage of the disease. Therefore, the aim has been to ensure adequate pain treatment, also in consultation with the pain clinic when needed. Naturally, all the other symptoms such as dyspnoea and mental anxiety have been treated at the same time. Some patients have died while

staying at the pulmonary diseases clinic, while some have been transferred to health care centres at the final stage of the disease. Dyspnoea, i.e. shortness of breath, may be alleviated using oxygen therapy, if the patient is suffering from the lack of oxygen observed in objective measurements. At home, the patient can get supplemental oxygen from an oxygen concentrator borrowed from the pulmonary diseases clinic. The oxygen therapy allows the patient to stay at home as long as possible, even up until his/her death.

Non-invasive ventilation therapy (NIV) is a treatment executed using a bi-level positive airway pressure ventilator with a nasal or face mask. This treatment is offered to patients suffering from progressive muscle weakness, mainly ALS patients. The treatment is usually initiated already before there is the need to start end-of-life care. The aim is that the patient uses NIV treatment increasingly as the disease progresses and continues the use until his/her death. During NIV treatment, the patient has time to adapt to the worsening respiratory failure and to the decision of refusing from respiratory therapy in form of tracheostomy with invasive ventilation.

The accumulation of pleural effusion may become a problem at the final stage of lung cancer or mesothelioma, i.e. pleural cancer. Previously, this symptom was treated by performing the patient a talc pleurodesis procedure, which means making pleural adhesions so that the fluid can no longer accumulate. The procedure is strenuous for the patient, because it includes the creation of a chemical inflammation, causing the patient fever and pain. The pleurodesis procedure has almost entirely been replaced by a tunnelled, thin drainage system (e.g. PleurX). Using the drain, the patient can empty the pleural effusion at home whenever needed, once or more a week. PleurX has proved to be a well-tolerated method.

Palliative sedation is a treatment in which the patient is held in light sleep to alleviate the symptoms. Sedation may be considered, if the patient is willing and if no other forms of treatment can be used to make the patient's condition tolerable. At the pulmonary diseases clinic, midazolam is used for the palliative sedation of the end-of-life care of ALS patients. The final stage of COPD often results in carbon dioxide narcosis, which makes the patient die calmly while sleeping. However, patients and their families are afraid of death by suffocation. The feeling of suffocation in the moments of death can be prevented by using opiates or other medicines as well as supplemental oxygen.

A guidebook "Alleviation of Shortness of Breath and Accumulation of Phlegm in End-of-Life Care" has been compiled for patients and their families as a development project. A staff guide is also under preparation titled "Alleviation of End-of-Life Care Patients' Shortness of Breath and Accumulation of Phlegm".

FUTURE CHALLENGES

The key challenge is the timing of bringing up the concept of end-of-life care. Despite the severe disease, the patient and his/her family have a natural tendency to hope for a cure and believe in recovery. It is, nevertheless, important to bring up the topic early enough. It is usually easier to discuss the unavailability of death with patients with advanced lung cancer and ALS than with patients with COPD. On the other hand, the patient may be relieved when a health care professional makes the first move in discussing the incoming death.

The decision on end-of-life care and the related DNR decision are usually made too late. This may, in some cases, lead to an unfortunate situation at home, as the paramedics may start to resuscitate a patient with, for example, advanced lung cancer. The reason for these types of incidents is the neglect of talking about death in advance, and then the panicky family member has been unsure of what to do when the patient has been dying.

Our goal is to rely more on intensified home care in the future, if the service is available in the patient's home municipality. End-of-life care provided at home can be considered a new opportunity in the North Karelia region. This presumes a focus on multidisciplinary cooperation and taking the patient's family members better into consideration. The patient staying at home and his/her family members should know who to contact when needing help. The possibility of dying at home also needs to be brought up. Today, there is a tendency to make a more active decision on end-of-life care; the decision is recorded on the patient's medical record with its own diagnosis code (Z51.5 Palliative or end-of-life care). Then, the patient will also get a DNR decision. At the final stage of end-of-life care, no unnecessary blood samples or other tests should be taken in order to refrain from increasing the patient's suffering. Also, no unnecessary medicine needs to be taken anymore. However, it may be difficult to stop giving antibiotics for a dying patient. Therefore, we are facing an important challenge as regards the medical and other treatment at the final stage of end-of-life care, when the patient is transferred from the pulmonary diseases clinic to the health care centre or home care.

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GOOD ENVIRONMENTS FOR END-OF-LIFE CARE BENEFIT EVERYONE

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One of the main objectives of the Paletti project has been to develop good environments for end-of-life care and palliative care. The project resulted in a description and visualisation of an end-of-life care environment that is neutral and culture-independent. The model incorporates various factors contributing to good environments. It includes several alternatives which can be used separately or combined to refurbish and redo already existing facilities or to design brand new units for end-of-life care. Planning a new hospice or hospital unit is one thing, but renovating an old building is quite a different matter. In designing an environment for end-of-life care, accessibility, ergonomics, safety, privacy and functionality are to be taken into account. Apart from these, attention should also be paid to atmosphere and cultural responsiveness. Furthermore, the design should enable the involvement of the patient's family and guarantee that the necessary instruments and supplies are practically located. The space should be adjustable to various user groups. As every user has a subjective experience of cosiness, it is important that the space is convertible. All these aspects necessitate a broader perspective on the design of care environments.

STARTING POINTS IN DEVELOPMENT

End-of-life care is an especially important phase because of the inherent human dignity and the special needs of the patient during the last days of life. In the same way, space planning has to meet the expectations and needs of the patient's family. Moreover, a well-designed environment helps the care personnel to maintain good quality at work, to handle difficult emotions and to fulfil individual care needs. In end-of-life care, the relatives are encouraged and guided to take part in patient care, but they are also

counselled to deal with sorrow and grief and to move on with their lives. Practical and comfortable environments enhance everybody's experience of good care and help to prepare for impending death, e.g. by reducing the feelings of guilt when the dying patient is offered the best possible care. The more vulnerable the person is, the stronger impact the environment has on him/her (Kotilainen 2014). It is a known fact that our sensory system actively adapts to the surrounding environment. However, it is still thought that visible objects do not play such an important role for the sick person if the care is good. It should be remembered, though, that even a blind person can describe how the space feels and that, apart from patients, also other people use the facilities. Thus, the environment counts.

In Finland, end-of-life care is mainly implemented in hospital environments that often suffer from the lack of privacy, poor indoor air quality, noise, irritating lights and the austerity of interior design. The nature and natural views, which are very important for many people, are often neglected in care environments. In this article, environment refers to the physical interior space of a care unit which is close to the patient and caregivers and which they all use.

The most essential instructions regarding space planning and construction can be found in the publications of the Building Information (Fi: Rakennustietokortisto). Additionally, Valvira, the National Supervisory Authority for Welfare and Health, and the Regional State Administration Agencies steer and supervise in matters relating to the establishment, quality and in-house control of treatment and care environments. When a new end-of-life care unit is being planned, sufficient space is an important concern (the recommendation is 20 m² per SRO). According to the Danish concept of end-of-life care, there should be 25 – 35 m² per SRO and

some space for a family member in a separate room. Often the cost-effective, fast construction and the room size and material choices bring the biggest challenges. These aspects have been taken into account in the model created by the Paletti project. The room that is modelled has 25 m² and it includes a patient care area, bathroom, mini-kitchen and some room to accommodate a family member.

Evidence-based design (EBD) has recently become more popular in the Western countries. Many international articles and projects, such as EHE and Hospice Forum Denmark, have stated that good care environments have a positive impact on the patient's body functions, as well as the work wellbeing of the care personnel. Ulrich et al. (2004) have studied the influence of care environments on patients and the care personnel. They found out that, among other things, a good environment causes decreased feelings of pain and stress, and increased experiences of safety. It also improves the overall quality of care and has an effect on the personnel's wellbeing at work. Nykänen et al. (2008) emphasise that evidence can also entail aesthetic qualities and social impacts of the environment. It is hoped that the model of the Paletti project will increase research interest in care environments.

The United Kingdom has actively developed hospital and care environments. The Paletti model utilised the recommendations of the Danish Model and the principles of care environment planning of the EHE Programme. These guidelines were also developed further with the help of photographs, discussions and a provincial enquiry. Moreover, benchmarking visits to the UK were made. The enquiry that was implemented during municipal visits considered the aspects presented by Kivelä in her literature review (2012). Those perspectives were further specified to analyse the importance of different variables in the creation of a good environment for end-of-life care. The solutions that promote family-centeredness, privacy, safety, cosiness and aesthetic values were found out to be very important.

Wayne Jonas has created a vision of optimal healing environments. It is based upon a thought that social, psychological, physical, mental and behavioural dimensions should be taken into account and enabled. Likewise, care should stimulate the inner capacity of a human body for self-healing. These facets were also included in the model of the Paletti project. (Ananth & Jonas, 2011.)

Colours, shapes and materials are fundamental to interior design. In connection with this, it is necessary to consider the key concepts of chromatics and to understand the effect of colours on a human being (Rihlma 1997). The visual model of a care environment created in the Paletti project also follows some of the Feng Shui principles. Especially the interaction of colours, materials and shapes is being observed. This subject has not been widely studied in Finland and, therefore, these solutions and their usefulness deserve to be discussed and studied.

In their thesis, Kallio and Iso-Markku (2012) discuss care environments from the children's perspective. The care environment designed by the Paletti project also caters for the children who visit their relative. If the environment for end-of-life care is designed for a paediatric patient, the principles of the model need to be adjusted and applied according to each child and his/her standpoint.

Background information for the design and modelling was collected from the municipalities and nursing homes by taking pictures of the current care environments and by implementing a Webropol online enquiry. Health care professionals, patients and students of practical nursing replied to the enquiry individually and collectively. A few respondents also answered on behalf of their relative as they were involved in the end-of-life care of their family member.

RESULTS REGARDING CARE ENVIRONMENTS

Palliative care patients' perceptions of good environments for end-of-life care

Often nursing homes have a separate room for the patient where his/her own furniture and decorative items, an ordinary bed and all familiar objects create the feeling of safety. It was emphasised in the answers that in hospital units the patients stay in the same rooms where they had been before, which means that there can be also other patients. Some respondents also commented that the environment is demanding and institutionalised because of its cold colour schemes and poor lighting. Some respondents described long-term institutional care as being "stripped bare". The ceiling lights are typically traditional fluorescence fixtures with tubes and grid lights. The walls are painted in greyish white. In hospitals, treatment and care is usually given

in double occupancy patient rooms. Some municipalities have units with separate rooms for patients in palliative and end-of-life care.

According to the nurses, they are not familiar with the use and opportunities of technology. They brought up an idea of the possibility to be in touch with the relatives via Skype. However, this idea had not been implemented yet. The colour or structure of the ceiling was seen as unimportant or less important. Instead, the in-service students considered colours and surface materials, as well as interior design and technology, more important. All respondents shared a similar view on the importance of allowing pet visits.

Health care professionals wanted to have larger rooms and enough space for the relative's bed or sofa-bed. In an ideal situation, the beds could be moved side by side. There was an expressed need to have lifting and moving implements and patient lifts, which should also be used more actively. There should be oxygen supply and suction equipment in every room. Moreover, there is a need for more chairs, ergonomic pillows, adjustable lighting with dimmers and more items of interior furnishing. The room for end-of-life care should have something delicate and beautiful, as well as a TV, radio, microwave oven and a fridge. Hospital linen and other textiles should be updated with a fresh and more colourful look. Matching furniture (desk, bed and dresser) and textiles (curtains, drapes, rugs and bed spreads) were looked for.

One student described that the desired environment should be "completely different from the institutional room where there is a bed, desk and curtains to separate one patient from the other". This statement also describes the environment where the future employees would like to take care of patients in end-of-life care. The environment should be practical and it should have colourful walls (light shades) and decorative textiles. There should be music if the patient so wishes and the indoor air should be warm and without draft. The students also commented that the positive and warm attitude of nurses and caretakers, unhurried encounter with the patient and sufficient care supply are also part of a cosy and comfortable care environment.

PRINCIPLES OF DESIGN AND EXAMPLES OF MODEL IMPLEMENTATION

Natural motives, elements and materials are an important part of a good environment. There are various options of how nature can be integrated into care environments, e.g. through gardens, flower arrangements or silk plants, or alternatively by having decals, print photos or stickers on plexiglass or glass. It is also possible to select textiles with natural materials or patterns. Moreover, nature can be integrated into ceiling paintings, acoustic elements or panel curtains.

The model room has black and white wallpaper with a delicate motif of a soaring or landing swan. It is a positive image even when a person viewing it has a negative emotion. Swan is a Finnish national bird with strong traits - it is a beautiful and graceful bird species. Similar courage is needed when encountering death and dying. The black



Figure 1. View of the room for end-of-life care.

and white wallpaper suits many different colour schemes. The ceiling has a painting with the blue sky and clouds. The painting is mounted to the ceiling in such a way that led strips or fluorescence tubes can be installed behind the picture. They give indirect, soft and lateral lighting. The ceiling decoration can be implemented by printing a digital picture to an acoustic board. General acoustic elements can include acoustic ceiling boards or wall panels and screens.

Silk plants in the room and bathroom add greenery. Small-sized green silk plans are suitable to many types of facilities and they soften corners. The colours of pots and flowers are chosen to match the other colours in the room. Round pots are preferred for their softer design language. Colour tones include the shades of metal, white, blanched oak or oak. Choosing too many types of timber creates anxiety and discord in the same manner as when there are too many or incompatible colours. Furniture should be kept simple and neutral, when it also stands the test of time.

There could be a blanket made of cotton, wool or sheep hide at the foot of the bed. The colour should match the colour scheme of the room, but it should not be white, because white is used in the bed linen. The white bed linen creates the feeling of cleanliness, airiness and lightness. Moreover, in an institutional setting bed linen should be washable at 95 degrees, which limits the colour options.

Lighting, air conditioning and adjustable ventilators (draft-proofing) and taking the effects of compass points into account bring added value to the environments for end-of-life care. Lighting can be made indirect by using daylight lamps and dimmers. Additionally, purposeful work, night and desk lamps are used. It is essential to consider the amount of daylight and its impact on colours. Moreover, the light output (luminosity) and colour temperature affect the tones and shades. In an ideal situation there would be daylight lamps or natural daylight through the window. Portable desk lamps add to homelike atmosphere and softness.

In the model, indirect spotlights and adjustable fixtures mounted to the ceiling, edges or walls together with the general lighting provide sufficient illumination, which helps the patient in spatial orientation. Individual objects have a meaning, too. A table lamp featuring a feather design would be in tune with the swan motif and make it alive in a delicate way. However, a simple basic lamp design with a round shade is also functional. The pedestal should be made of brushed steel, because the shine and hardness of polished chrome can irritate. When designing hospital rooms, the headboard panels or wall rails often have an integrated lamp attached to the power, oxygen and suction outlets, as well as to a holder for a suction container. In such a broad light source, it is essential to



Figure 2. View to the ceiling, bathroom and mini-kitchen.

consider the luminosity and directional projection of the up-light fixture. A beam of light projected to the wall can accentuate e.g. a beautiful picture or a decorative wall text.

It is important to take care of the draft-free ventilation, fresh air supply and the right room temperature of the room for end-of-life care. At the end stage, breathing becomes more difficult and extra oxygen and light breeze can make the feeling more comfortable. However, the cold and harsh draught caused by excessive ventilation is not good for the patient. In the summer, the room can become too hot and then an air-source heat pump is a reasonable option – as long as it is not installed in such a way that it blows cool air directly onto the patient. In the model room, there is a place reserved for the heat pump above the kitchen cabinets. **Users' ability to orientate themselves in the space creates the foundation for serenity and usability.** Functional environments are based on privacy, good signage, accent lighting and accessibility. In the model, one flooring material is used for the whole area, but another shade of the same material is used to create a rug-like pattern, which shows the care area and creates the feeling of space and ambience. In the bathroom, the colour changes to light grey. The tone is close to the medium grey shade of the swan-motif wallpaper. There are no sills or thresholds as required by the accessibility guidelines. There is a colourful accent wall in the bathroom, which becomes fully

visible when the corner sliding doors are opened. The glass allows light to pass through, but provides a sufficient level of privacy when opal glass or decals are used.

By illuminating wall and ceiling surfaces differently, various items can be accentuated, attention and gaze directed and atmosphere created. In this model, a led strip is fixed behind a picture that is mounted to the ceiling. It provides soft, indirect light for nights and mornings. There are two general light sources, e.g. a recessed light fixture or flush-mount ceiling light, which makes the space look more homelike. They give light to the work area and passageways for the nurses and relatives alike. In front of the window, there are ceiling-mounted led spotlights. One of the spots can illuminate the flower bucket on the table, the other the area before the window and the third one the soaring swan of the wallpaper. In the bathroom, general lighting is indirect as the fluorescence tubes are fixed behind the moulding or the edges of the ceiling panels. In this way, light flows down evenly on the wall surface and does not dazzle the patient on the shower gurney (stretcher). Additionally, there is a separate lamp above the mirrored cabinet and a general light source in the ceiling, which can be used when necessary. In the kitchen area, led strips mounted below the cabinets illuminate the work area and the colourful accent wall adds an architectural feature and colour to the white cabinets.



Figure 3. Room view from the entrance.

Signage, such as room numbers, must be clear. A number plate or other identifier is attached to the upper part of the door plate on the side of the corridor. There is no need to highlight that the room is aimed at end-of-life care. Instead, a sign with a text, picture or other symbol could be attached to the door to convey the idea of tranquillity and quietness. In the present model a bird is used as an effect and the same symbol could be used outside the door as well.

Colours are chosen according to the compass orientation and the direction of the window. If the windows face West or East, warmer tones of colour are used than if there is light exposure from the East or Southwest. In the sunlight, room colours reflect completely different tones. They become stronger and more vibrant. If yellow-green colour hues are used excessively, they may be too bright or warm when the sunlight from the South adds to the yellowness. Cooler blue or beige hues are used if there is a desire to maintain the feeling of freshness. On the shady side, warmer tones of yellow bring life to the room and are therefore a good choice.

In the present model, the colour scheme was carefully chosen so that the tones could be used as background colours in either orientation (in direct light or shaded conditions). These tones include light sky blue (G366) or soft beige (Y462). These tones can be matched with a light hardwood floor, oak-effect flooring or monotone white, medium grey or light beige vinyl flooring. Parquet or laminate floors are not recommended for public buildings because of their lower abrasion resistance. They are also more slippery and harder to keep clean. There are, however, materials that have a wood-like effect, such as acoustic vinyl cork flooring, which is also water and shock proof, and pressure resistant.

White (F503) can be used as an accent colour in small proportions. It has a slightly hard and clinical effect similar to the white colour used in furniture and hospital beds. In shady corners, white mixed with beige or yellowish tints should be used. The most commonly used pure white tone is not recommended. A brighter tone brings more airiness and freshness to the room. Other access colours include petrol blue (K366), yellowish green (J387), fuchsia (L338) and cyclamen (S338). They can also be used together. However, yellowish green is recommended for rooms with West or Northeast facing windows. Privacy and dignity are taken into account when planning the convertibility and use of the room. The patient's wish for good care environment for the last days of his/her life can be already taken into account in the advance care directive (i.e. living will). The wishes regarding

care environments can be recorded in the care directive or expressed in the care plan during palliative care. What personal items should be brought to the room? Which of the items is the most precious to the patient? Which picture gives strength or soothes the patient? Which type of music or scent pleases most? In this way, the patient is surrounded by familiar objects, his/her favourite music, pleasing smells and the people that matter most.

In the model, the mini-kitchen and the bed for the relative are in the same room, but the kitchen area is further away from the patient. The kitchen is important as it creates an ambient scent environment that can affect the patient's appetite, providing s/he still has the sense of smell left. Additionally, 100% pure essential oils can be used to give a fresh ambient scent. The furniture is white. The desk



Figure 4. View to all areas of the patient room.

of the mini-kitchen is made of a stainless steel counter with an integrated sink and build-in stove. The stainless steel is seamlessly integrated with a grey laminate countertop with a base cabinet that can be locked. The locker can be used to store the relative's personal items. The upper cabinets include a dish-draining closet and shelves to store dishes, as well as a place for a microwave oven. The cabinet doors are painted with a pure white colour and the upper cabinet is low. The relative's bed can be moved next to the patient's bed when needed. A CD player or important small decorative items can be placed on a dresser.

Family-centred solutions and communication with relatives is enabled. Moreover, when needed, the doctors can be consulted e.g. through a smart TV or webcam (Skype). Online landscape photos, music and programmes are used. The relatives can stay overnight as there is a box-spring divan bed with a cover on top. During the daytime, the bed is converted to a sofa by adding pillows with subtle patterns and carefully chosen colours. The cushions and pillows make a backrest and headboard for the divan, which creates a peaceful abode. There is a lightweight movable chair in the room. Some space is left between the patient's bed and the divan bed for necessary rearrangements. The hospital bedside table is either white or steel and has wheels and a drawer with a lock. The patient him/herself might not be able to use it, but the care personnel or relatives can make use of the table or tray and the drawer. Flowers, photos or decorative items can also be placed there for the patient to admire.

The feeling of safety and cosiness is made of familiar things and functionality of the space. In addition to the design factors described earlier, the feeling of safety is affected by cosiness and familiarity. The layout of personal items, TV, radio, tablet, the belongings of the child guests and the place of medical equipment have to be carefully thought through. The dresser and the wall-mounted coat rack provide some storage space. The TV set is also wall-mounted with the help of a swivel. It is placed between the patient's bed and the wall with a window opening. It is important that the TV can be out of sight when needed and that it does not block the view through the window. Child visitors are taken into account by providing them a kit with drawing paper, colour pencils, card games for various ages and toy medical kits to reduce fears and to help to deal with pain and suffering. In the dresser, there could also be sound or music toys, such as an interactive sound book.

Durability and economic efficiency steer also interior design. To add to the solutions mentioned before, all surfaces should allow washing and disinfection. The overall colour tone of surfaces is white or warm white (e.g. F503 or 503), which then is accentuated by the chosen colours. The use of colourful textiles or textiles with big patterns is carefully considered. When the sensory system deteriorates, it is better if the sensory stimuli are as neutral and unambiguous as possible. White is a good colour for both painted and tiled ceilings. On a white surface, a painting, glass pattern, mosaic or acoustic panel with art or photo prints become clearly visible.



Figure 5. There is room for convertibility.

White, washable paint can be used instead of sky blue also on the wall with a window opening whenever the other colours or colour combinations are brought to the room in form of curtains. In the plan, the wallpaper with a swan motif restricts the colour choices of the adjacent wall. The tranquillity and harmony of the room needs to be maintained, but the colour impression should not become too cold.

The wall with a window is light sky blue (e.g. Tikkurila G366), which creates a frame for the natural view from the window and matches with the swan motif. The wall behind the patient's headboard is also painted with the same colour. There is a print decal above the power and oxygen supply and suction equipment. The colour of the decal is chosen to match the colour scheme. In this model, it is dark brown. Black text is not recommended because it is hard and creates strong contrast.

The swan-motif wallpaper, which is actually a custom-made water-resistant wallpaper with a print photo, is used on the whole wall surface. Alternatively, it can be replaced by a natural motif roll-up poster, in which case, the wall is painted white. There could be various scenery, plant, sky or animal themed roll-ups for the room.

The end panel of the mini-kitchen cabinet is painted with an accent colour, either fuchsia or yellowish green, or with the same beige tone as the side wall. The walls with accent colours form a nice background for the furniture. They also highlight e.g. indoor plants, textiles, pots, side lamps and photo frames.

The environment makes use of art, music and handicraft. When the theme of the picture is well chosen, it generates positive associations for the patient, his/her relative and the nurses alike. In the model a print text is visible to the relative and the nursing staff. The text, "You matter because you are", is a translation of the principle by Dame Sicely Saunders, the founder of the end-of-life care movement. According to this principle, end-of-life care of a dying patient should be based on the individual, his/her needs and symptoms. Bed linen, blankets, curtains and other textiles follow the chosen colour scheme. Small patterns are avoided. The divan bed has a background of a beige wall that matches with very light grey textiles. The grey colour also unifies the metal colours of hospital furniture and makes a good background for more colourful pillows. Likewise, it combines well with the wallpaper and flooring. Pillows, blankets and curtains are preferably monochrome. Long window drapes cover part of the wall and also hide any exposed pipes. The curtains both soften the image and absorb sound and, thus, improve room acoustics. The selection of fire-retardant fabrics for public buildings is limited and, therefore, it is easier to find the desired colour for the wall surface than for the curtains. White curtains are always an option. Nowadays there is a fabric spray that can be used to make cotton fabrics fire retardant, which makes patterned textiles also possible. However, it is important to remember that simple patterns that match the colours of the room are the best choice for curtains. Simple is beautiful.

Paintings and pictures can have various themes according to the patient's taste, but they should match the existing colours of the room. Music can be played e.g. using an Internet connected smart TV or tablet, or on a cd player. *Beauty for the senses – small things can have a great impact.* Spatial illusion can be created by adding a photo wallpaper or a painting or by using light shades on walls and adding narrow areas of accent colours. Mirrors can also create an illusion of space, but mirrors should not reflect anything disagreeable. It is important to consider where to hang a mirror especially in a room for end-of-life care. The sky painting in the bathroom adds space. The harmony is also preserved when the bathroom colours match with those of the room when the sliding doors with safety glazing are left open. The view from the window should open to the nature and there should be some free space by the window. If the room has radiators, they are concealed by covers with vertical slats to allow the air to pass through.

The radiator cover makes also a window sill. The medical equipment are in small containers also when stored in the drawer. They can also be stored in small, decorative boxes on the table. The boxes can be made of braided plastic or metal. Most importantly, they should be easy to clean and able to hide small items. On the wall shelves, there are small decorative glass items, such as small tea light holders. Their purpose is to enliven the space, not to illuminate, because candles cannot be burned indoors. However, it is possible to have a LED tea light.

Contemporary style and convertibility are the key principles of interior design. Furniture is chosen according to the needs and number of users. The mini-kitchen and portable furniture such as the chair, side table, drawer and divan bed allow changes in the room if the family member wants to take part in end-of-life care. Paintings can be replaced by a green wall. Alternatively, there could be a matching painting that is not hanged on the wall, but placed on the wall shelf. Roll-up posters could be used more to enliven the walls and to better match the patient's taste.

The toilet and bathroom design should take into account the health and functional ability of the patient. Bathroom fixtures are chosen carefully so that there is space in the middle of the room. There should be room enough for the patient to access the shower with a walker, shower wheelchair or a mobile shower bed. There should also be room for the caregiver and therefore, the shower room is spacious. If the patient is able to move independently or the room is used by other persons, there should be additional safety bars and handles. There is a wall-mounted safety rail and a folding shower chair, where the patient can sit after his/her bath. The shower has a height-adjustable nozzle. The toilet seat can also be electronically height-adjustable and have adjustable arms. There is space around and behind the toilet for patient transfer and assistance. The toilet is wall-hung when it can be accessed with a wheelchair and the requirements for the turning radius are met. There is a corner mirror cabinet above the bathroom basin for storage. On the sidewall, there is also another wall-mounted cabinet and bathroom towel hooks. A horizontal window up on the wall allows natural light and an outside view, but it still lends privacy. The fixtures are white and the walls have the matching tones of the colour scheme. The flooring is monochrome non-slip bathroom vinyl or tiles. The ceiling is either plain white or painted with a decorative technique. In the model, the walls are light beige and accent green.

Waterproof vinyl sheets are used both on the floor as well as on the walls of the wet area. Colour is added by bringing in plants, colourful textiles and a wall cabinet.

APPLYING FENG SHUI

The principles of Feng Shui were applied to the interior design, for example, by creating spaces according to Yin and Yang and by including the five elements of the Wu Xing theory. The patient is placed away from the line that extends from the door to the window. Only the foot of the bed can be in that area. If the patient is lying between the door and the window, s/he is more distractible to the outside stimuli. A similar bedroom layout can also be found in the Danish model for palliative and end-of-life care.

If the patient's bed needs to be between the door and the window, the patient's gaze can be directed by various effects or visual blockers, such as folding screens, dividers, shelves or decorative effects. It is good to place the headboard of the patient's bed against the long wall, which allows the patient to see to the door area on one side and to the window on the other. There should be something beautiful to view straight ahead. According to Feng Shui, the question is not about what the room looks, but rather what the room feels like. Our bodies react to the stimuli as a whole. The same principle is observed when choosing the place of rest for the relative. Only a short time is spent by the window or on the isles and therefore movable chairs are best for those areas. According to Feng Shui, the patient should not be lying under hanging or pointed objects. Therefore, surface-mounted lights which do not cause dazzle are a good way to illuminate the space. Moreover, indirect lighting reflecting on the surface of the walls or ceiling can be used.

Additionally, the five elements of Feng Shui (Wood, Fire, Earth, Metal and Water) can be applied. Each of the elements is supported, regulated and restrained by the others. When the compass points and directions are taken into account, the balance of the elements enables choices that create harmony. Each of the elements has its own pair of organs in the body, as well as colours, circumstances, seasons, emotions, forms, materials, and a particular sense associated with it. Colours and forms can easily be applied in interior design, but also material choices can create harmony. Colours play an important role in creating the desired atmosphere. The harmony in chromatics is different from the harmony according to Feng Shui. In Feng Shui,

Colours and forms can easily be applied in interior design, but also material choices can create harmony. Colours play an important role in creating the desired atmosphere.

the universal energy, Chi, should flow in a balanced way. Colour is only one attribute of the element. The space is harmonious when forms, materials, pictures and patterns are all taken into account. The light colour emphasises the forms, while the brightness accentuates the colour. The harmony and disharmony created by the intensity, radiance and combination of colours should be considered as part of good interior design. (Banks 2007, Hytönen 2003.)

Orange, red and the shades of purple represent the element of Fire, which in the human body correspond to psyche, sleep, circulation, heart and small intestine. The earthy colours, such as yellow and brown, represent the element of Earth, which in Chinese medicine and in Feng Shui is associated with the digestive system and spleen. The element of Metal incorporates metal shades, white and grey with respiratory organs and the large intestine. Black and dark blue are colours that are associated with the element of Water and they support urination, the lymphatic system, and hormonal and mental functions. The element of Wood is attached to green and turquoise colours. They maintain emotional balance, joints and sinews, creativity, and blood circulation and purification.

Wood and other natural materials, except wool, balance emotions and support planning ability and creativity. Natural elements such as real flowers and indoor plants invigorate the mind, purify the air and remind of the natural biological cycle. However, the soil of houseplants contains spores and plant care can also be challenging. Still, it is important that the environment for end-of-life care includes natural wood, plants, cotton or pictures of nature.

Animals, materials derived from animals as well as art representing human beings or animals belong to the element of

Fire and have a balancing effect on the patient's mind. They function in the same way as dynamic forms, real fire and different shades of red. In big portions they invigorate body functions, especially the heart, and can cause excitement, even anxiety. Therefore, they are used carefully in very small doses. For instance, a family photo, wall decals or the white wallpaper with a swan motif do not yet create restlessness. However, if the swan wallpaper would be very close to the patient, it would constantly activate the patient and increase his/her anxiety.

The element of Earth is integrated in the plan with the choice of light beige and darker square accent area on the floor. The model uses pure white in the mini-kitchen, on the walls, doors and in the drawer, as well as some grey to represent the element of Metal. These choices support especially the master of energy, i.e. respiratory organs. They also create the illusion of space and increase lightness. They do not cause irritation to sense organs. A moderate number of metal items have the same effect. The element of Water can be found naturally in the bathroom faucets and shower. Moreover, windows and mirrors can also be taken to represent Water. Thus, black can be used minimally e.g. in small decorative items, flower pots or textiles. The excessive use of black should be avoided in care environments as it can create perceptual voids. However, it is a good background colour e.g. for a small-scale photo gallery. The element of Wood is incorporated to the plan by using a cotton bed cover on the divan bed, backrest pillows with a flower theme, silk plants and wooden furniture. The element of Fire is added only as an effect in the animal-themed wallpaper, in a lampshade, in flower pots and a wool blanket.

CONCLUSION

In her article, Kotilainen (2014) asks if it is possible to create a warm environment and caring culture for hospitals. Based on the development work and experiences from the pilot study of the Paletti project, we can answer that the will is already there. The design of environments for end-of-life care stems from the needs of the dying patient and from the care culture and the attitudes of the nursing personnel towards the patient and their own work. The physical environment is one important element in the implementation of good care.

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PERCEPTIONS AND VISIONS OF PALLIATIVE CARE IN NORTH KARELIA

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There are approximately 170,000 inhabitants living in the North Karelia Hospital District. The number of treatment periods at North Karelia Central Hospital is almost 30,000 each year. The main areas of specialisation dealing with fatal diseases include lung diseases, surgery, neurology, oncology, internal medicine, and intensive care. In 2012, 382 patients died at North Karelia Central Hospital, i.e. on average one patient a day. When inspecting the total number of treatment periods at North Karelia Central Hospital, 1.3% ending up in a patient's death.

It is estimated that approximately 15,000 people are annually in need of end-of-life care in Finland. More than half of them can be treated at home or with the help of home nursing. Other patients in end-of-life care require treatment at a hospital or in a hospice. In North Karelia, the number of such end-of-life care patients is approximately 400-500 per year.

When a serious illness is diagnosed fatal and there is no possibility for recovery, it is time to move on to end-of-life care. The duration of end-of-life care is from a few days to several weeks. Previously, specialised health care has not had a procedure to be followed in such situations. Thus, it is important to plan the end-of-life care process at single hospitals and in the entire North Karelia region. For this purpose, a series of meetings was held already in 2012, charting the end-of-life care procedures in North Karelia. The main conclusions of the meeting series were as follows: the most essential fields of specialised health care will be appointed a coordinating doctor and a coordinating nurse. In case of a serious illness, the treatment procedure will be discussed with the patient and his/her family. The final objective is to coordinate regional palliative and end-of-life care.

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This series of meetings led to the initiation of the Pal-etti project, in which various actors cooperated in order to create an extensive operating environment. North Karelia Municipal Educational and Training Consortium, Karelia University of Applied Sciences and North Karelia Central Hospital and Honkalampi District have worked as partners in the project.

A model of treatment for both specialised and primary health care is being developed for different diseases. According to this model, a dying patient can be treated at home or, if necessary, at the health care centre or at a hospital. It has been excellent to discover that all fields of specialisation have been involved in this project, including cancer diseases, lung and heart diseases, neurological diseases, liver and gastrointestinal diseases, kidney diseases, surgical and intensive care diseases, and children's diseases.

During the past century, people's life expectancy has risen. Even in the early 1900s, the average age of a dying person was less than 50 years, and the most common causes of death were different infections. Since the 1950s, the life expectancy has been over 60 years and the most common causes of death are now cardiovascular diseases, neurological diseases, accidents and cancers. Today, the life expectancy has risen up to 80 years, i.e. it has risen with more than 30 years over the past century.

We are, indeed, aware of current and future challenges, including medical evolution in various fields of specialisation, the rise of the average age of the population, and the increase in the number of seriously ill patients. If we can also predict these situations, we can meet these challenges here in North Karelia and solve the problems efficiently.

As the medicine has developed, the course of cardiac diseases, for example, has changed significantly. Today, the development of the treatment of myocardial infarction has led to a reduction in the size of an infarct and the mortality rate of infarct patients at the hospital and during their first year after the infarct has decreased significantly. Efficient cardiac care has improved patients' prognosis even with dozens of years. During the last decade, the treatment of severe heart failure has also changed and improved the prognosis of these patients and their coping at home. Moreover, cancer treatment possibilities have greatly improved the prognosis of cancer patients. Surgical results, effective radiation therapy and cancer chemotherapy have considerably improved the results of the treatment of cancer. As the medicine has developed, the prognosis of some

previously fatal diseases has become good. Today, a new group of patients consists of patients who get a second serious disease as they become old.

The demographic change in a society means changes in the age structure. The number of people over 65 years of age in North Karelia is approximately 36,000 at the moment. In 2030, this number is estimated to be 52,500, i.e. an increase of more than 16,000 people. Most of them are older people with at least moderate health. The future challenge in health care is to provide appropriate resources for the treatment of sick people, and these opportunities should be available to all age groups. It is, however, a reality that part of the diseases, especially the ones confronted by older people, are so severe that the patient's health care needs to be turned into palliative and end-of-life care. The future challenge in health care is to organise this appropriately.

At the same time, the quality of life of a dying patient and his/her family should be humane. In the future, the aim should be that the dying person - no longer a patient - would be rather surrounded by people close to him/her than health care professionals. And finally, that the dying person could stay in a desired place, which often seems to be some other than the hospital.



POSSIBILITIES OF PHYSIOTHERAPY
AND EMERGENCY CARE IN
MULTIDISCIPLINARY COOPERATION
IN PALLIATIVE AND END-OF-LIFE CARE



PHYSIOTHERAPY IN A MULTIDISCIPLINARY PALLIATIVE CARE TEAM

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INTRODUCTION

In the future, palliative care and end-of-life care will become more and more significant areas of care as the ageing of the population continues. In Finland, it is estimated that 200,000-300,000 patients are in need of palliative care each year, and approximately 15,000 patients are in need of end-of-life care (Sosiaali- ja terveystieteiden ministeriö 2010, 11). According to Tilastokeskus (2013), North Karelia had a population of 165,754 in 2012. When making a relative comparison with the share of palliative and end-of-life care patients in Finland and the population of North Karelia, it can be estimated that there will be approximately 6,100-9,160 palliative care patients and 458 end-of-life care patients in North Karelia each year.

Palliative care is implemented by a multidisciplinary team, which can or should also include professionals in rehabilitation. Physiotherapy has a role to play as part of palliative care, but no Finnish material or a collection of guidelines is available on palliative physiotherapy so far. Members of multidisciplinary teams should communicate more about their areas of expertise (Aherne 2005, 11). This article is based on a thesis conducted at Karelia University of Applied Sciences (Karelia UAS) in 2014, trying to meet this challenge. The thesis is titled "Physiotherapy in a Multidisciplinary Palliative Care Team".

The thesis was commissioned by the Paletti project. The thesis will be published on the project portal and on Open Repository Theseus for publications from universities of applied sciences. The thesis will help physiotherapists and other health care professionals perceive the physiotherapeutic methods that can be used as a support for palliative care. The aim is, therefore, to deliver information on physiotherapeutic practices to the multidisciplinary team. However, the use of these methods and practices requires evaluation and a plan of implementation by a professional physiotherapist.

PALLIATIVE PHYSIOTHERAPY

Palliative care is aimed at patients with a life-threatening disease. Palliative care does not aim at hastening or postponing death. The goal of the care is to improve the quality of life of the patient and his/her family by, for example, helping the patient live as an active life as possible and alleviating pain and other symptoms caused by the disease. (World Health Organization 2013.) A multidisciplinary team is considered to be a prerequisite for good end-of-life care and the main principle of palliative care (Borda, Charnay-Sonnek, Fonteyne, & Papaioannou 2013, 84; Sosiaali- ja terveystieteiden ministeriö 2010, 25; World Health Organization 2013). A multidisciplinary approach is essential for a successful implementation of palliative care due to the various and complex problems related to palliative care. The focus in multidisciplinary cooperation is not only on the importance of the professional expertise of the participants but also on cooperation between the different groups of professionals, on valuing the variety of expertise involved, and on the development of cooperation in order to implement good patient care (Anttonen 2011, 1 - 3).

Physiotherapy is known to have been involved, for example, in cancer treatment since the 1960s (Laakso 2006, 781). Palliative physiotherapy is one of the life-enhancing methods of treatment for a dying patient (Kumar & Anand 2008, 138 - 146). Physiotherapy aims at promoting, maintaining and restoring an individual's physical, mental and social well-being by striving for the best possible physical performance and ability to function. The goal of palliative physiotherapy is to reduce the side effects of the disease or its treatment on the individual's daily life. (Watson, Lucas & Hoy 2009, 771.) The objectives of palliative physiotherapy can be very simple, such as painless sitting on a bed or participation in an important social event (Watson et al. 2009, 771).

METHODS OF PALLIATIVE PHYSIOTHERAPY

Palliative physiotherapy is not limited to the treatment of different types of cancers (Laakso 2006, 781). The different methods of palliative physiotherapy can be applied to the treatment of the symptoms of e.g. cancer, neurological diseases such as Parkinson's disease, amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS), HIV (Kumar & Anand 2008, 138-146), AIDS, and cardiovascular diseases (Laakso, McAuliffe & Cantlay 2003, 781). The physiotherapist has the chance to avoid the common "mistake" by family members and health care professionals who might consider functional impairment an integral part of the clinical picture, which leads to the remaining physical function not being properly utilised (Frymark 2009, 8-9).

Physiotherapists have the knowledge on e.g. functional anatomy and ergonomics. They can analyse movement, posture and body positions in relation to the environment. Physiotherapy aims at maximising functional capacity, promoting independence and empowering patients for active adaptation. Physical activities implemented under the guidance of a physiotherapist can undo the negative effects of physical immobility, at the same time improving mental well-being. Physiotherapy aims at helping the patient optimise his/her functional capacity, taking into account the interaction between physical, mental, social and professional dimensions (National Institute for Clinical Excellence 2004, 12; Santiago-Palma & Payne 2001, 1049-1052; Watson et al. 2009, 771).

Palliative physiotherapy utilises general physiotherapeutic methods and treatments in consideration with the patient's clinical picture (Frymark 2009, 8-9). Physiotherapeutic methods can be applied already at an early stage of the disease, alongside with other forms of treatment and therapy (Watson et al. 2009, 771). Physiotherapeutic methods can be used to influence a number of physical sub-areas, such as pain, mobility, strength/weakness, control of malformations, coordination and balance, gait, respiratory symptoms, physical endurance, and strength development (Kumar & Anand 2008, 138-146). Physiotherapeutic exercise methods can, for example, be used to improve one's balance and the strength of the upper body. These qualities are needed, for example, in transitions and in the use of a wheelchair. In addition to instructing and giving guidance in transitions and in the use of aids, physiotherapists can guide nurses, personal assistants and family members in

the implementation of passive movement exercises and position management and in assistance in transitions. (Watson et al. 2009, 771.)

Palliative physiotherapy can be used not only for making patients learn how to manage their long-term symptoms, but also for providing them with new content or meaning for their lives. An open and supportive rehabilitation environment provides a sense of hope. After a therapy intervention including physical exercise, patients can experience improved physical well-being as their mobility, muscle strength and endurance have improved as well as their mental well-being. Patients may also feel more positive, relaxed and receptive. An improved ability to do one's everyday activities gives a feeling of improved life management, which contributes to one's optimism. By improving the patient's mental and physical well-being, physiotherapy can restore the sense of togetherness between the patient and his/her own life and the environment, allowing living instead of just being. (Belchamber 2013, 136-139.) Physiotherapy is also important at the stage of end-of-life care. Then, the focus is on giving advice and guidance, but e.g. physical training can improve the patient's quality of life even at that stage (Santiago-Palma 2001, 1049-1052).

INTERNATIONAL CARE GUIDELINES

Since the concept of palliative physiotherapy is still relatively unknown in Finland, no Finnish physiotherapy guidelines or other source material describing the variety of methods used in palliative physiotherapy is available on the subject. The thesis conducted on the topic aims to present an overview of palliative physiotherapy and its methods. The theoretical part of the thesis defines the concepts of palliative care, palliative physiotherapy and multidisciplinary team. A literature review was used to find information on physiotherapeutic methods. The review aimed at answering the following question: "Which methods of physiotherapy do the international palliative care clinical guidelines for multidisciplinary teams recommend?"

The purpose of the literature review was to search for information on international care guidelines to be used by multidisciplinary palliative care teams, which would be comparable to the Finnish Current Care Guidelines. The information retrieval focused on national or regional, publicly available guidelines written in English and the review was conducted from a sample of 11 guidelines selected based on their high quality. The guidelines mainly concerned symp-

tomatic treatment of a dying patient, but some long-term palliative care guidelines were also included in the study. The types of symptoms requiring physiotherapy or physiotherapeutic methods were selected from the guidelines. The international guidelines were then combined with the Finnish Current Care Guidelines and with a Finnish handbook for registered nurses (Atula 2013; Janes 2013; Kassinen 2013; Kokkinen 2012; Käypä hoito -suositus 2012).

The results of the literature review were described verbally and summaries were made in form of tables (Appendix 1, page 82). The tables describe the application of the different methods in the physiotherapeutic process of a palliative care patient. Physiotherapy terminology was used in the physiotherapy process (Kuntaliitto 2007). Symptomatic treatment of a dying patient proved to be the most prominent element according to the review. Guidelines were available for the physiotherapeutic treatment of the following symptoms: spinal cord compression, gastrointestinal symptoms (nausea, vomiting, constipation), lymphoedema, fatigue, respiratory symptoms (shortness of breath, cough, death rattle), pain, spasticity, and mental symptoms (insomnia, anxiety).

The literature review highlighted the following physiotherapeutic methods: therapeutic exercise and physical activity, aids, position treatment, orthoses, breathing exercises, relaxation exercises and techniques, adaptation techniques, massage and particularly lymphatic massage, and methods of physical therapy (electrical treatments such as TENS, heat and cold therapy, and acupuncture). In palliative physiotherapy, guidance and counselling have an essential role alongside with individual therapy. For example, physiotherapists may instruct the medical personnel or with home care patients, instruct the patient's family members in the implementation of position treatment, assisting in transitions, and in using different aids.

The results of the literature review have been presented in form of tables at the end of this publication, divided according to different symptoms. The tables have been compiled roughly in the same order as in the Finnish guidelines for palliative care patients.

APPLYING THE METHODS IN PRACTICE

The thesis provides professionals with an indication on the physiotherapeutic treatment of palliative care patients' symptoms. The review may also be useful for physiotherapists working with palliative care patients. Based on their

” Palliative physiotherapy can be used not only for making patients learn how to manage their long-term symptoms, but also for providing them with new content or meaning for their lives. An open and supportive rehabilitation environment provides a sense of hope.

education and professional competence, physiotherapists can implement effective physiotherapy for palliative care patients, even if they are not specialised in palliative physiotherapy. The variety of methods used in palliative physiotherapy is, however, wider than presented in the thesis.

Country-specific practices and regional differences in the allocation of tasks among the various groups of professionals imply that not all facts discovered in the literature review can be directly applied to the practice as described in the original guidelines. For example, a physiotherapist working for public health care in Finland is not allowed to practise massage as a form of treatment. Similarly, some original guidelines described methods that are to be implemented by an occupational therapist in some countries, but are to be partly implemented by a physiotherapist in Finland. An example of this includes evaluation of aids used for moving and daily activities, which is something mostly done by physiotherapists in Finland.

The duty of professionals specialised in palliative care is to educate new professionals and to participate in the establishment of a service structure providing palliative care of highest quality possible (Institute for Clinical Systems Improvement 2011, 7). One of the aims of the Paletti project is to develop the structures and practices of palliative and end-of-life care. From this aspect, another relevant objective is the development of expert and consultation

practices for acute symptoms difficult to be controlled as well as the development of basic and supplementary education. (Paletti 2013).

The thesis presented in this article is utilised in palliative care training organised by the project. These trainings are aimed at both health care and physiotherapy professionals and students. In addition, the thesis will be published on the portal for palliative and end-of-life care for North Karelia developed by the Paletti project, where it will be freely available for people developing care and treatment. The thesis has also been published in the Open Repository Theseus (<http://urn.fi/URN:NBN:fi:amk-201405117101>). The thesis is available for professionals in palliative and end-of-life care, which will hopefully stimulate the utilisation of physiotherapeutic skills in the care of palliative patients.

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POSSIBILITIES OF PHYSIOTHERAPY

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The methods used in physiotherapy can help to increase and maintain a person's ability to function, or delay the decline of this ability. The ability to function is related to coping, which means that one is able to perform important everyday activities. It is important to get support to using the remaining resources in everyday life. An open and encouraging environment creates the feeling of hope and it should be remembered that we are working together to find the solutions. This way the quality of life may increase so that life is pleasant and rewarding and as independent as possible. The relevance of activity is significant for all people. The methods of physiotherapy aim at activating functionality, alleviate pains, increase muscle strength and exercise balance. The methods try to achieve as good an experience as possible about coping in everyday life. (Hautamäki & Seppälä 1998; Kopponen 2013.) With physiotherapy, the clients learn to control their symptoms in everyday life and thus enable new thoughts and activities to be included in their life. This way everyday life can include new things that enable the change in the values and meaning of life.

VARIETY OF POSSIBILITIES

Reduction of movement, immobility and a long bed-rest cause various problems. Weakness and immobility can lead to postural anomaly or motor control problems. This causes extra strain on soft tissues and joints and produces extra pain. Problems are also caused by the weakening of muscular strength and endurance, decrease in the flexibility of ligaments and tendons, decrease in bone mass and density, weakening of lung ventilation, decrease in mucus extraction from the lungs and pressure increase in capillary system which causes swelling. (Kopponen, M. 2013.) Thus, it is important to notice all aspects of functional ability.

”” The relevance of activity is significant for all people. The methods of physiotherapy aim at activating functionality, alleviate pains, increase muscle strength and exercise balance.

Balance exercises should be done on a daily basis. Poor balance and muscular strength increase the liability of falling down and getting injured. Everyday chores, group exercise and gardening are examples of good exercises. When doing the exercises it should be considered that one does not hold one's breath and that the movements are made within the limits of pain.

It is important to consider independent exercise, which can be supported by the family assistants or nurses, all with their own expertise. Changing the environment to being more activating and independent performance of everyday activities as well as possible is enabled by supplying various assistive devices or by altering the interior arrangements in the home. Everyday activity in one's own home supports coping with the resources.

Various activities improve the physical well-being as mobility, muscular strength and endurance increase. All in all, a person's condition is more positive and relaxed. The increased ability to do everyday activities gives the feeling of improved life control, which further helps to increase hopefulness. Improving the physical well-being helps retaining the sense of belonging. It also gives the sense of controlling one's own life and surroundings, thus supporting the condition of living and not just being. (Hautamäki & Seppälä 1998; Kopponen 2013.)

Regular physical exercise is important. It includes movements, positions and activities which are thought out in advance. The purpose of exercise is to prevent injuries, assist activities, minimise risks, optimise overall health, or to contribute to physical condition and well-being. The exercises im-

prove, for example, balance and upper-body strength. These qualities are required in moving and getting in and out of a wheelchair. Besides planning and giving individual instruction, the physiotherapist can guide nurses, assistants and family members to help with the exercise movements. It should be remembered that even one single exercise time can produce the experience of well-being and even lessen dizziness. The physiotherapist will define the number of exercises, but alongside with the number of exercises, the most important thing is to have motion, even one movement at a time. (Toikka 2012.)

Balance exercises should be done on a daily basis. Poor balance and muscular strength increase the liability of falling down and getting injured. Everyday chores, group exercise and gardening are examples of good exercises. When doing the exercises it should be considered that one does not hold one's breath and that the movements are made within the limits of pain. As a rule, there should be enough rest between exercise times. It is worthwhile to link the exercises to everyday situations, like getting up from the chair or getting up the stairs. When doing muscular strength and balance exercises, it is essential to do as much as possible standing up and use walking as a part of the exercise. Muscle pump exercises for the legs are important if mobility is restricted. They assist the blood circulation in veins and thus prevent vein thrombosis. The muscle pump operates when pumping the ankles up and down. This improves the blood circulation in the legs and thus reduces the risk of vein thrombosis. (Toikka 2012.)

It has been shown that exercise has an effect on the improved mood, increased energy and social well-being of people suffering from the fatigue syndrome. Physical activity can reduce the symptoms of depression with older people and improve the mood significantly. The fatigue syndrome can involve weakness, tiredness, sleepiness, lack of motivation, boredom and apathy. The symptoms will not ease with rest but with exercise. Especially in connection with long-term immobility, it is essential to increase exercise even slightly. Well-planned, moderate exercise has been shown to be useful even at final phases of life. Touching the patient, holding the hand or light massage can alleviate the symptoms. Relaxation exercises and the use of heat pack can also be worth trying. (Kopponen 2013.)

Exercise should also be increased in the treatment of constipation, whenever possible. Peaceful movement, rubbing the stomach or applying heat can be of help. Shortness of

breath is a very common and an extremely disturbing symptom in many terminal illnesses. To alleviate it, breathing and relaxation exercises and peaceful movement can be tried. It is also important to assess that the physical performance equals the everyday strain. Positive expiratory pressure exercise by blowing in a water bottle and the right respiration technique may also result in alleviation. (Kopponen 2013.)

When treating pain with the methods of physiotherapy, cold and heat therapy are recommended. Heat can release endogenous opioids, thus alleviating pain. Transcutaneous Electrical Nerve Stimulation, also known as TENS, eases pain by making use of low voltage electrical current with electrodes placed on the area of pain. It is used widely because it is well tolerated and alleviates pain. Various relaxation techniques can also be used, as well as postural management. (Kopponen 2013.)

Pain can be prevented and alleviated with postural management. This treatment is especially important with patients who spend long periods of time in one position. Changing the position frequently enough is important since it can reduce the stimulation of pain receptors and stiffening of joints and prevent the occurrence of pressure ulcers. Changing the position is also vital because it improves blood circulation, eases respiration and relaxes. (Heimonen 2014)

The position should be changed every two hours. Wedges and pillows, sand bags, rolls, slings, head rests, leg rests and supports, special beds and mattresses can be used in postural management. The position is supported so that the limbs can be moved. The support is recommended to be put around the body to give a sense of feeling one's limbs and body. (Toikka 2012.)

The most common positions for a bed-patient are supine position, side position, psoas position and semi-supine position. In postural management, the best results are obtained when the patient changes positions frequently. The most commonly used rest position is the supine position. It is not, however, the best position considering vital functions: breathing becomes shallow and vein circulation slows down. The function space for the organs decreases as they are pressed against the spine and muscular tensions increase causing stiffness. (Heimonen 2014; Toikka 2012.)

In the side position, the patient is supported behind the back and shoulders with pillows into decline of about 30-40 degrees, either forwards or backwards, preferably

forwards. The head and neck are supported so that the cervical spine is aligned with the thoracic spine. The limbs are supported in a slightly bent positions with pillows. (Heimonen 2014; Toikka 2012.)

The semi-supine position is more natural than the supine position considering social interaction, and more functional than e.g. the side position. The supine position is acquired by using either the adjustments of the bed or by supporting from the back with large pillows. It is wise to put a small pillow to support the lumbar region, so that the natural bend of the lumbar spine is kept. Pillows positioned under the arms support the elbows at an angle of about 90 degrees. The brachia are kept slightly apart from the body. In this position, it is good to turn a "roll" around the body to give a sense of feeling of the outlines of the body. (Heimonen 2014; Toikka 2012.)

In the psoas position, the legs of the patient lying on the back are supported with a psoas pillow or with regular pillows so that the hip and the knees are bent and above the upper body. The psoas position eases the pain in the back by reducing the pressure towards the lower back. (Heimonen 2014)

The awareness of the significance of micro-positioning has been growing lately. A healthy person who is lying down makes about eight to forty micro-movements per hour. Micro-positioning mimics this movement pattern. With micro-positioning it is possible to get physiological position changes in the joints and it relieves the pressure at the head, shoulder, hip and thigh. Micro-positioning suits everyone whose movement has been restricted while in bed. Micro-positioning prevents pressure ulcers, pneumonia, thrombosis, and contractures. Micro-positioning can be done whenever dealing with the patient in everyday life. Most often, the patient is lying in the centre of the bed and a "nest" or a low base is made for the patient out of a sheet, a towel or a fleece cover and the edges of the nest are slowly moved outwards from under the patient whenever a nurse comes to see the patient, a few centimetres at a time. There is no need to remove the patient's own cover, and there is not necessarily a reason to touch the patient at all. (Toikka 2012.)

Micro-positioning means changing the position only as much as it is necessary. The patient is not turned from one side to another or otherwise moved very much, but only so much that the pressure towards the skin changes places and the harmful consequences are avoided. This way sleeping can continue uninterrupted. (Toikka 2012.)

Kinesiotherapy uses assisted or passive movements when the bed-patient no longer can perform the movement fully or at all. In this case, the patient should be informed about the activity and he should be involved step by step in the movement on the level of thought. The movements provide experiences of the body and its movements, improve the ventilation of the patient's lungs, improve blood circulation and oxygenation of tissues and prevent pressure ulcers. The largest joints should be supported with an extensive hold during the movement. The joints are stretched and flexed as much as they allow movement. This should be done slowly without pain and the pace of the movement should be calm. The passive movement also maintains the mobility of joints, thus enabling painless basic care because the limbs must be moved during washing or when changing diapers. (Heimonen 2014; Toikka, 2012.)

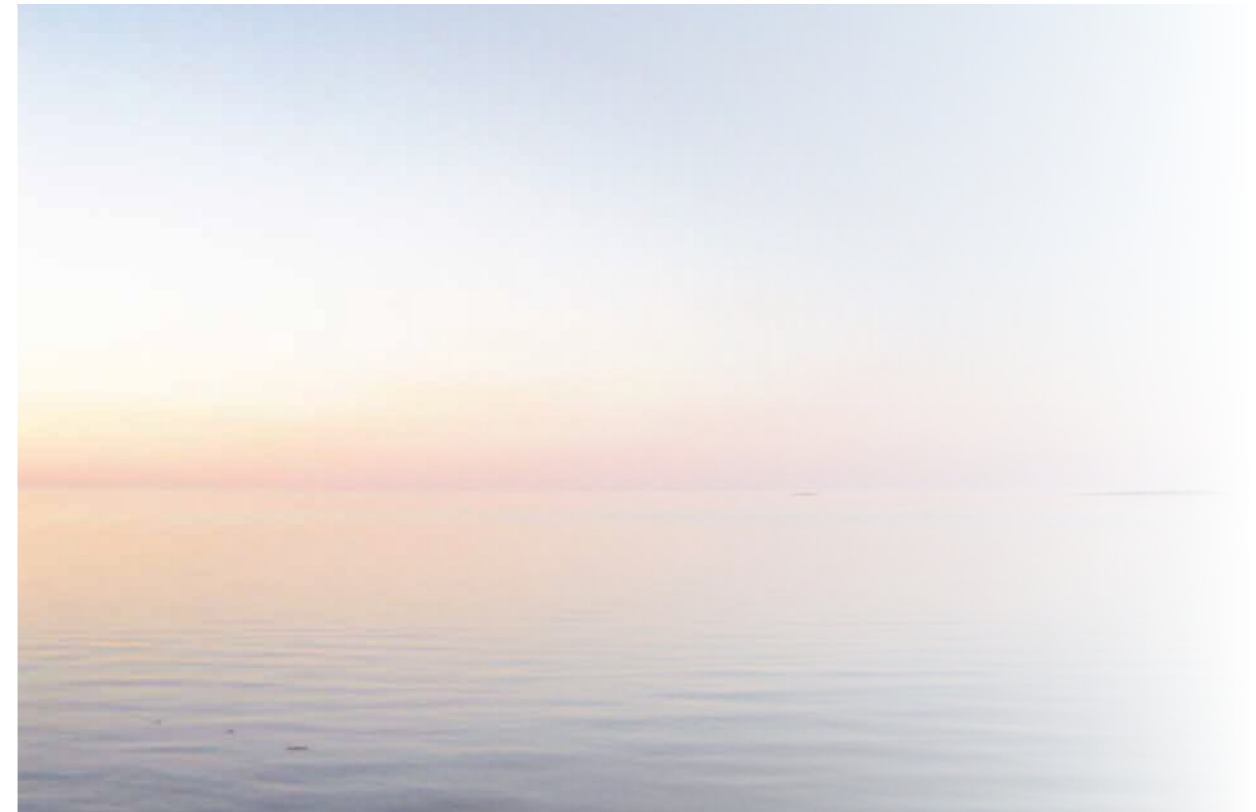
Nature has a great impact on rehabilitation. Nature is a factor promoting well-being and health. Strolling in nature gives opportunities to maintain overall well-being, not just physical condition. Reaching the goals is easier and more unnoticed in nature. For example, improved balance when walking on a forest path is a good physiotherapeutic effect resulting from nature. The central nervous system does not get similar stimuli when moving indoors as when moving outdoors and it has been noticed that mobility is better retained when there is regular outdoor exercise. (Juvonen & Ratilainen 2014.)

Fresh air and the diversity of nature also have a positive effect on appetite and the quality of sleep. Moving in nature is a refreshing experience. The seasonal changes in nature increase the interest to follow the course of nature and thus also increase the awareness of the season and even of days. The scents in nature activate the senses and evoke memories. A garden in the surroundings of the yard may induce some exercise by tending plants. Picking apples or berries, raking the autumn leaves and just pottering about in the vegetable garden is good exercise. Being outdoors has thus a great impact on well-being. (Juvonen & Ratilainen 2014.)

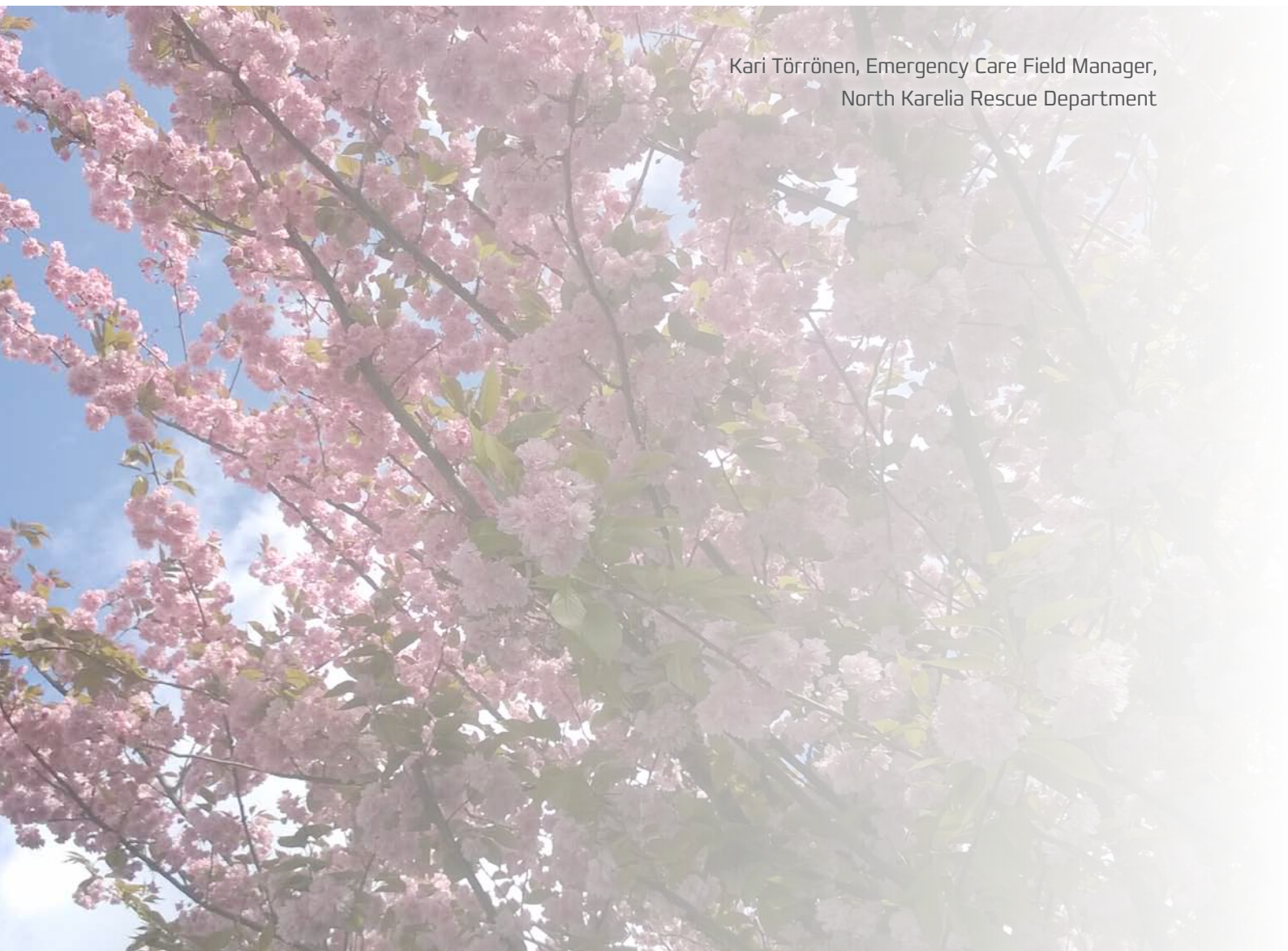
The greenness and verdancy of nature motivate into participating and social interaction. Being in nature is relaxing and reduces stress. In addition, it lowers the pulse rate and reduces muscular tensions. It has been noticed that elevated blood pressure decreases already after 20 minutes in nature. The stress hormone cortisol level in blood is also reduced and the number of leucocytes which increase resistance gets bigger. The maximum positive effect of being in nature is reached in two hours and the effect will last for several days. (Juvonen & Ratilainen 2014.)

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EMERGENCY CARE AS PART OF THE CARE PROCEDURE OF A PALLIATIVE CARE PATIENT – CHANGE IS POSSIBLE



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BACKGROUND

The quality and availability of social and health care services have been improved in recent years. A good example of a successful area of improvement is emergency care. Today, joint municipal authorities for medical and social services have the responsibility for organising emergency care, as defined by the Health Care Act. Municipal ambulances no longer exist.

North Karelia Health and Social Services Consortium (PKSSK) has decided to implement regional emergency care services in full cooperation with the North Karelia Rescue Department. A field management system has been created to ensure as short response time as possible and a minimised number of situations when no ambulance is available in some region. Field managers work together with emergency service dispatchers, estimating and monitoring situations at all times.

The varying levels of emergency care in municipalities led to the need for a reform. The differences resulted from differences in the paramedics' level of education and the immediate ambulance preparedness. Today, there is only one emergency care service provider in North Karelia, which ensures an equal level of emergency care services.

EMERGENCY CARE SERVICES ARE ABLE TO MEET THE NEED FOR END-OF-LIFE CARE

The current service structure and educational requirements are based on the new Health Care Act: an ambulance providing advanced care needs to have a Bachelor of Health Care (Paramedic) and a Bachelor of Health Care (Registered Nurse). The North Karelia Rescue Department employs approximately 80 advanced level paramedics at the moment. As a result, the Department is able to meet the municipal needs for the care of palliative patients on an equal basis.

“Familiar ambulance boys came in, found out that it was nothing serious and gave me some oxygen. I got to stay at home. After all, nothing could have gone better for a sick person.”

PROCEDURE FOR THE EMERGENCY CARE OF A DYING PATIENT

Municipal home nursing services are responsible for the care of palliative care patients outside institutional care. In the inner city area of Joensuu, intensified home care services are available for patients in home care around the clock. As a result, these patients need emergency care more rarely. In other municipalities and localities, home care services are usually provided until 4 pm or 9 pm. As a consequence, the significance of emergency care is emphasised in these locations due to the lack of a round-the-clock service. In many localities, emergency care is the only health care unit available 24/7. In addition, emergency care has the responsibility to support home nursing e.g. outside working hours or in busiest periods of time.

Instructions for the care of a dying patient are currently under preparation (protocol for the symptomatic treatment of a dying patient). The contents of the protocol differ from the customary role of a paramedic, as paramedics have been trained to save lives and keep people alive in all circumstances. Thus, the normal emergency protocol is not useful for patients with a decision on palliative care, as the aim of the treatment in such cases is not saving the patient's life, but rather implementing and supporting symptomatic treatment. In such a situation, the paramedic needs to be present and empathetic, alleviate the patient's suffering and possibly listen to the worries of the patient's family members. As regards patient transfers, palliative care patients always have a special right: if a palliative care patient needs to be transported to a ward, s/he will always be transported in an ambulance, regardless of his/her condition.

The new situation requires, therefore, a new protocol and training for the protocol. Change in the attitudes is also necessary - the paramedic's work is still important and necessary, although from a new and different perspective. The instructions must be clear enough, since the paramedic is eventually in charge of the final estimation of the patient's condition and care. If necessary, the paramedic can consult a doctor on call.

Communication and the role of emergency care
Good communication is essential for emergency care. The emergency care personnel has to know regional palliative care patients and decisions made relating to these patients need to be clearly recorded and easily found wherever the patient happens to be. Every palliative care patient must

have a so called authorised place in a municipal health care centre, where the patient can be transported directly when needed, without a visit to the hospital emergency clinic, regardless of the time of day. Sudden and surprising incidents that one has not been able to prepare for are also challenging, e.g. when a patient might be outdoors or visiting a friend and does not carry the palliative care decision with him/her.

When the paramedic arrives at the scene (e.g. the patient's home), the paramedic makes an immediate assessment of the situation and tries to solve the problem and perform the possible treatment at the scene. If necessary, the paramedic consults a doctor on call and informs the patient's permanent caregivers on the treatment that has been provided. A palliative care patient can have the following types of symptoms, for example, at home: pain, shortness of breath, accumulation of phlegm, nausea, constipation, diarrhoea, urinary retention, bleeding, cramping, problems related to care equipment, decline in the general state of health, uncertainty of family members, and fatigue.

VALUES REGULATING THE CHANGE

Most palliative care patients wish to be at home and also die at home. The protocol for the symptomatic treatment of a dying patient helps the paramedic to support the patient's own will and allow a valuable and dignified death. However, this requires training and continuous supervision.

The new practice also supports the family members of a palliative care patient being present and involved in the palliative care process. Family members are often relieved e.g. after being provided with a number for the local ambulance which can be contacted directly when home nursing services are not available. This also contributes to the principle of guaranteeing the good death of a palliative care patient also from family members' point of view.



OPERATIONAL MODELS FOR
DEVELOPING COMPETENCE IN
PALLIATIVE AND END-OF-LIFE CARE



PROJECT IN END-OF-LIFE CARE AS A STEPPING STONE TO THE CREATION OF A SHARED STUDY MODULE

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The initial idea of creating a shared study module arose after the project actors within the Paletti project had decided upon the practical measures and implementation of the project, based on project objectives. A mutual desire was discovered for creating a basic-level study module in developing palliative and end-of-life care competence as part of the curricula of registered nurse students at Karelia University of Applied Sciences (Karelia UAS) and practical nurse students at PKKY (North Karelia Municipal Education and Training Consortium), including both youth and adult students and multi-form students.

After setting up the goals, current educational models used at Karelia UAS and PKKY were clarified. The need for a new study module on the subject of palliative and end-of-life care in the students' curricula was also charted. As a result, it was discovered that the contents of the implementation plans of the curricula at both institutions suffered from a lack of palliative and end-of-life care education and practical exercises. Karelia UAS students' observations and views on the theme were also enquired before the planning of the education. The students experienced that the information they received on the subject was partially fragmented. The Paletti project offered an excellent opportunity to face this challenge and create a unified module on the subject.

Encouraged by the results of the charting, a shared educational study unit with common course objectives, contents, scheduling and materials was decided to be established to be used by both institutions. In order to implement successful end-of-life care, the basic abilities in care need to be mastered. End-of-life care cannot be studied as a single subject, but the basics of care and treatment need to be considered as part of good palliative care. Based on this view, this shared development work was not only limited to the compilation of material on end-of-life care, but the entire study module focusing on nursing interventions was

renewed. The new study unit will be implemented both in practical nursing education and in registered nursing and public health nursing education during the first year of studies, regardless of the areas of specialisation or areas of expertise. The study unit deals with learning about care from different aspects; basic care, interaction skills, aseptic techniques, monitoring of the condition and state of health, aids, and end-of-life care.

A shared online learning environment was also created in Moodle as part of the study unit. The Moodle platform is used by both students and teachers as a learning environment and material database. The Moodle course was created on the basis of the implementation plan of the course, and the areas of responsibility were appointed according to each planner's specific competencies and areas of expertise. A Second Life environment was also linked in Moodle, in which students create their own avatar characters and can independently practise contents related to palliative care. The Second Life environment also contains an assignment on spirituality, which allows students to deepen their perspective on the subject alongside with the topics of single lessons.

The online learning environment also serves as a tool for teachers and provides each teacher of the study unit with a complete package on the topics of the course. The topic of end-of-life care is its own theme as one part of the study unit, thus enhancing the foundation upon which students build their competence at the different stages of the curriculum.

Practical training lessons are an integral part of the course. In these lessons, students get to practise methods, activities and manual skills of helping taught in the theoretical lessons in a safe environment, guided by teachers. According to the implementation plans, practical training lessons are scheduled reasonably in relation to corresponding theoretical lessons, which allows both teachers and students to go through a safe and natural learning path.

The Paletti project has been enabling us to get material on end-of-life care created by older students to be used by teachers during the study unit. The purpose of this material is to utilise new teaching methods and to show student perspective in the teaching. Teachers do often contemplate the variety of new methods to be implemented in study units.

One of the specific areas of development discovered during this educational cooperation was more extensive utilisation of teaching methods. Simulation exercises were selected as one area of development. The term simulation refers to a teaching and learning method, which simulates a real situation with a corresponding environment, situation, equipment and psychological reality (Miller et al. 2008). Simulation exercises have been found to have a clear effect on the knowledge and skills of nursing personnel (Falcone et al. 2008). In particular, team working skills have been improving during simulation exercises (DeVita et al. 2005, Wisborg et al. 2006, Wallin et al. 2007, Bergman et al. 2008; Falcone et al. 2008, Miller et al. 2008). Simulations have been particularly useful for practising difficult and rare situations, since any possible mistakes made during the practice will not cause patients any suffering (Reeves 2008). For example, research data can be found on such simulation exercises regarding emergency situations in childbirth and care of new-borns (Miller et al. 2008, Henrichs et al. 2009), determining the priority of patients' treatments, i.e. triage (Wolf 2008), orientation of a resuscitation team to the facilities of a new hospital by creating simulated resuscitation cases in various departments at the hospital (Villamaria et al. 2008), crisis management, practising with ethical issues, and detection of medical errors (McFetrich 2006). In the light of this information, simulations can also be seen as a good method for practising end-of-life care.

A complete package on end-of-life care simulations was created during the planning process and it will be tested with registered nursing and practical nursing students in December 2014 in the simulation learning environment Simula at Karelia UAS. The idea is to conduct these simulation exercises in multidisciplinary teams consisting of both registered nursing and practical nursing students. Teachers from both organisations will also participate in the simulations. Thus, the purpose is to employ this method and the simulation pedagogy more widely in the future.

After the pilot stage, the aim is to stabilise the practice to be implemented by other groups as well. At Karelia UAS, all new groups of registered nursing and public health nursing

students will participate in these simulations already during the current semester. The new curricula for registered nurses and public health nurses planned for Karelia UAS in 2013-2014 (Karelia-ammattikorkeakoulu 2014) already includes this shared study unit. All teachers in this course will use the online learning material created during the project. PKKY uses national implementation plans from year 2010 (Pohjois-Karjalan Koulutuskuntayhtymä 2010), but a team has been set up to renew the curricula and the criteria for vocational qualifications will be renewed as of 1 August 2015. End-of-life care will have a stronger foothold in the new curriculum and the results of the project will serve this reform. After the piloting of the course, experiences will be collected from both organisations, which allows us to develop the course and its teaching methods further in the future.

The creation of a shared study unit and all the related meetings and negotiations have brought about much more than we expected at the beginning of the project. We have become familiar with the different practices of both educational institutions and we have shared a great deal of useful ideas for lessons and for students' independent learning. We have had the opportunity to compare the contents and extent of our education and found a lot of similarities to be utilised during our cooperation. During this project, we have been able to acquire more knowledge from each other and update our skills. Our team spirit has been excellent and we have felt empowered after each team meeting. One example of such an empowerment during the project was our benchmarking trip to London on 6-10 April 2014. During the trip, we visited three hospices. Some considerable differences between the educational systems in Finland and in the U.K. were discovered during the trip. For example, health care organisations (e.g. hospices) in London provide the education themselves, also in cooperation with the university. A mutual understanding on patient support was discovered during the visits: we fully agreed on the fact that the patient should be seen as an individual both in teaching and in clinical work and we should support the patient until the end of his/her journey using multidisciplinary collaboration. During the trip, the participants also acquired a whole lot of intellectual capital to be utilised in their own teaching.

The network of partners created during the project will certainly be utilised in the future too as a low-threshold communication channel for catching up, sharing our thoughts and supporting one another. This way, we have contributed to the development of competence in end-of-life care.

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SYSTEMISING COMPETENCE DEVELOPMENT THROUGH A MODEL FOR CONTINUING EDUCATION AND TRAINING

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INTRODUCTION

The National Advisory Board on Social Welfare and Health Care Ethics, ETENE, has since 2011 regularly surveyed the implementation and development of end-of-life care in Finland. The three surveys that have been conducted by now indicate that despite the improvements in its implementation and development, the availability and quality of end-of-life care still vary. (ETENE 2012.) These results are also applicable in North Karelia. In addition to the ETENE surveys, several earlier projects (e.g. The Development of Palliative Care in 2005 – 2009, HomeCare24 in 2008 – 2011) show that the organisation of palliative and end-of-life care is insufficient. This makes the patients' clinical pathways disconnected and causes variation in care quality. There are no specialised end-of-life or palliative care units and the competence in palliative and end-of-life care varies. (Paletti project application 2012).

One of the main objectives of the Paletti project has been to strengthen the competence in palliative and end-of-life care. This objective is pursued by developing and harmonising the course supply and practices of palliative and end-of-life care in the local basic and continuing health care education and training. Regarding continuing education, the project aims at developing an interactive, multimodal and process-like model. (Paletti project application 2012.) The model will help health care actors collaborate seamlessly and divide tasks appropriately.

Continuing education and training in health care supports professional practice. It is systematic and driven by the needs of the population or the personnel/organisation. It aims at ensuring effective and high-quality care for the population, securing the operational preconditions of the health care system and enabling the life-long growth and development of employees. The Decree by the Ministry of Social Affairs and Health (1194/2003) on the updating,

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in-service training of health care personnel and the recommendations on the implementation of updating training (Ministry of Social Affairs and Health 2004) especially emphasise the importance of follow-up and assessment as means of holistic development of training. The responsibility for follow-up lies with the organisations and with the Local Government Employers (KT), which collects follow-up data from these organisations (STM 2003; STM2004).

The demand for the competence development pursued by the Paletti project is based on both the health care needs of the population and the training needs of the health care personnel and organisations (ETENE 2012, Paletti project application 2012). The starting point for the model for continu-

ing education and training is the recommendation given by the Ministry of Social Affairs and Health, which is based on a tripartite framework of care. The first level of end-of-life and palliative care is represented by all health care units that provide the basic services of palliative and end-of-life care. The second level contains the regional units of palliative and end-of-life care that perform specialised care in their respective regions and give consultation to other units. The third level consists of the palliative medical units and specialised end-of-life care units working alongside university hospitals. In these units, patients are able to receive advanced-level care and treatment. Additionally, these units have a role in teaching and research. (STM 2010a; STM 2010b; PKSSK 2014).

STUDY ON CONTINUING EDUCATION AND TRAINING IN PALLIATIVE AND END-OF-LIFE CARE IN NORTH KARELIA BEFORE THE PROJECT

The current state of palliative and end-of-life care education and training was studied with the help of the persons responsible for continuing education and training in the partner organisations. Of the project partners, North Karelia Health and Social Services Consortium (PKSSK) already had an established process of competence development, which included annual needs analyses conducted among the personnel in basic public health care and special health care. The process of competence development was part of the ONNI human resource management system, which also included a regional training calendar. The current course supply at PKSSK is based on the needs analyses and includes themes of palliative and end-of-life care. Furthermore, PKSSK coordinates the provincial network and training of pain management nursing, which is an important part of palliative and end-of-life care.

Karelia University of Applied Sciences (Karelia UAS) had earlier organised several specialised studies (30 cr.) on cancer patient care, palliative care and pain management. During the survey, apprenticeship-type training on palliative care for higher education was being planned in cooperation with Turku and Satakunta Universities of Applied Sciences and it was implemented for the first time in January 2014. In connection with the earlier development projects on palliative care, the personnel of the province had received training on the special issues of palliative and end-of-life care. Over the years, Karelia UAS has also provided personnel training

for various organisations. Since 2011, Karelia UAS has organised Autumn Seminars on Palliative Care in North Karelia.

The Adult Education Centre of the North Karelia Municipal Education and Training Consortium (PKKY) has offered staff training consisting of four afternoon sessions. Moreover, palliative and end-of-life care has been an integral part of the vocational upper secondary and specialist vocational qualifications that are completed through vocational skills demonstration. From autumn 2014, the Specialist Qualification in Care for the Elderly has included a module of Care of the Dying Patient, which can be completed either as a separate course module or as part of the Specialist Qualification in Care for the Elderly.

LEARNING NEEDS REGARDING PALLIATIVE AND END-OF-LIFE CARE AS PERCEIVED BY REGIONAL ACTORS

At the initial stage of the Paletti project in spring 2013, all provincial health care centres and private care units were approached with an enquiry in order to investigate the implementation of and training needs for palliative and end-of-life care. Additionally, information on individual learning needs and the situation of continuing education in palliative and end-of-life care was collected from the participants of the seminar conducted in autumn 2013.

The answers were in line with the results of ETENE (2012) and former projects of Karelia UAS (Paletti project application 2012): The availability and quality of palliative and end-of-life care varied greatly and there was a strong demand for competence development. The respondents considered important that palliative and end-of-life care is included in both basic and continuing education. They also commented that the latter should be provided at both regional and organisational levels. It was emphasised that training should be frequent and regular and the acquired knowledge should be quickly transferable to the health care practice. The respondents thought that the whole personnel, including medical doctors, needed such training. According to the replies, the topics of training should cover general aspects of palliative and end-of-life care. The persons who provided more detailed information on their learning needs requested training in pain management, holistic care and encounter with the patient and his/her family, the special requirements of various patient groups, living will and advance care planning, nutrition and fluid replacement. Support for employees' coping with work was also seen as essential.

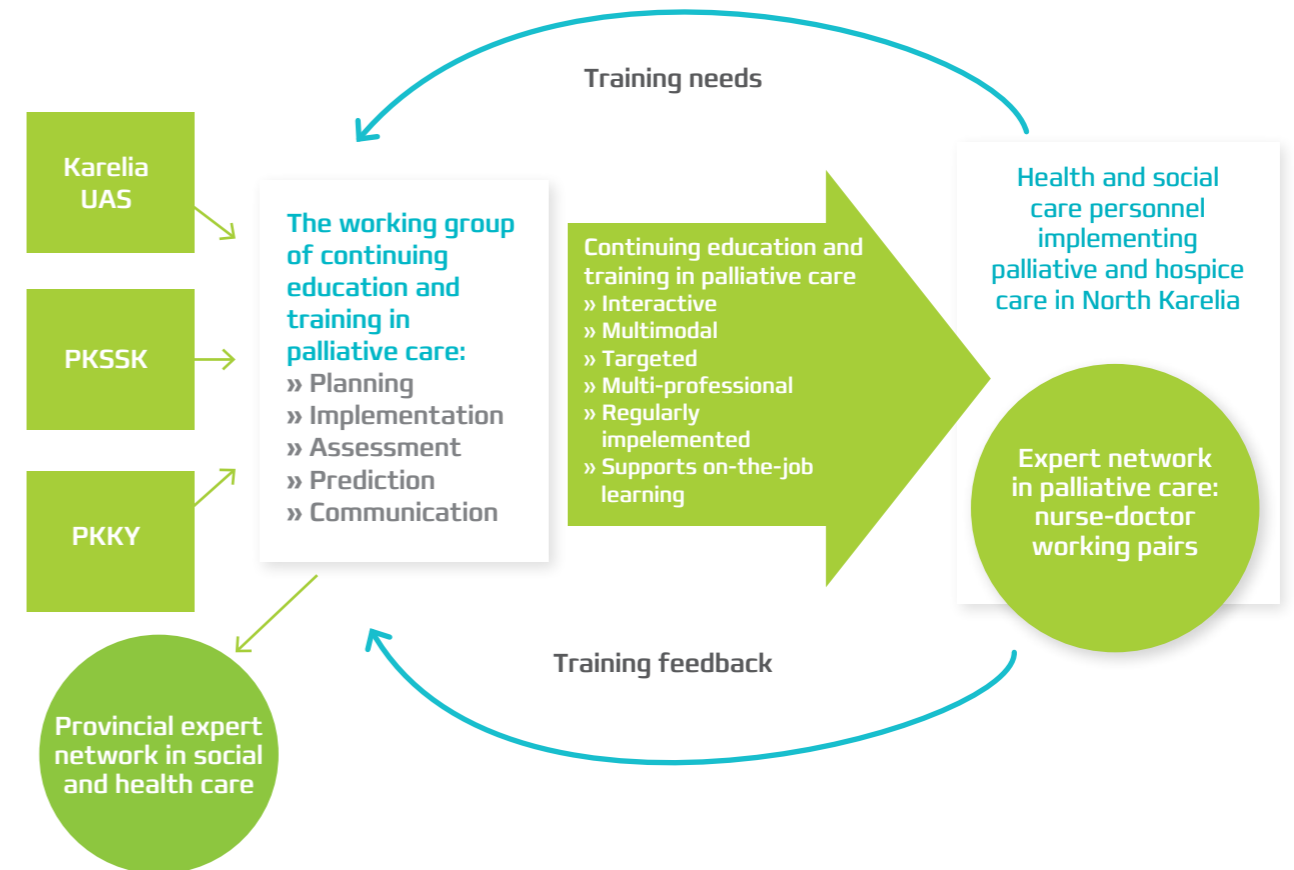


Figure 1. The provincial model for continuing education and training in palliative care.

THE MODEL FOR CONTINUING EDUCATION AND TRAINING IN PALLIATIVE CARE

After investigating the situation before the project and analysing the learning needs, the modelling of continuing education in palliative care was initiated. The model was developed by Team 2 of the Paletti project consisting of the persons responsible for continuing education and training in the three partner organisations. Team 2 met 1 – 2 times a month from autumn 2013 to spring 2014. Ideas for the model were also generated in an innosession, in which all project workers took part. Moreover, the sparring group of the project commented on the model and provided ideas for further development. The actor having a central role in the

network and the coordinator of the model for continuing education in palliative care (Figure 1) is the working group of continuing education and training. The nominated coordinator has the responsibility to implement the model after the project, which safeguards the future of the model. The persons responsible for the working group and acting as conveners are the registered nurse and the doctor who coordinate palliative care in PKSSK. The other members include the training manager of PKSSK and the representatives of Karelia UAS and PKKY, two persons from each. The task of the working group is to predict, plan, implement and assess the continuing education and training in palliative care. It will also regularly evaluate the functionality of the model.

The working group of continuing education and training in palliative care is part of the provincial expert network in social and health care.

The working group of continuing education in palliative care meets from two to three times a year. The coordinating registered nurse collects the provincial training needs every other autumn by sending a questionnaire to the expert network in palliative care. Additionally, the training manager of PKSSK conveys the coordinating registered nurse information on the training needs that are identified in the annual needs analyses of the organisation. Based on the summary made by the coordinating registered nurse, the working group prepares a training plan and a bulletin, which is published on the portal for end-of-life care on the PKSSK web site, in the ONNI training calendar and which is also sent as a separate announcement to the provincial expert network. The number of participants is monitored and feedback is collected in order to evaluate the balance between training needs and supply.

The model for continuing education and training in palliative care incorporates some earlier training programmes on palliative and end-of-life care of the partner organisations. According to the new model, the content of training programmes is planned together. The training programmes include e.g. joint thematic seminars, an online course (5 cr.) on palliative care planned together by Karelia UAS and PKKY, the course supply of PKSSK and separate courses and tailored training sessions. All training packages use IT applications, e.g. in video conferencing and online lectures. Participatory and experiential learning methods, such as the simulated learning environment of Karelia UAS, the end-of-life care model of PKKY, case studies and workshops, are used. The training courses are realised in collaboration with the provincial expert network in palliative care. Furthermore, the materials available on the portal for end-of-life care of PKSSK are being used.

One of the main objectives of the model is to provide well-planned, targeted and purposeful training for health care personnel. Various training sessions and courses form a whole, in which several educational products complement each other and enhance in-depth learning. On-the-job learning is also taken into account when the training programmes are being planned, which makes it easier to

apply and transfer the acquired new knowledge into action across organisations. Completion of courses and qualifications alone does not guarantee sufficient competence development or continuous professional growth. The model has also complies with the recommendation given by the Ministry of Social Affairs and Health on a tripartite system of palliative and end-of-life care. While the general courses in basic education provide skilled professionals to all levels of health care (Level I), continuing education and training give health care professionals a possibility to update the basic skills and knowledge and to receive advanced-level training on palliative and end-of-life care required at Levels II and III. (STM 2010a; STM 2010b.)

CONCLUSION

The Paletti project will end in spring 2015, after which the model for continuing education and training in palliative care will be deployed. The dissemination and implementation of the project outcomes is facilitated by the fact that in autumn 2014 PKSSK decided to establish a palliative care unit as per the national recommendation. The employees of the unit (the coordinating registered nurse and medical doctor) will be the key persons in the working group of continuing education in palliative care. Supported by the new unit, the development of palliative care can continue in the future.

The model for continuing education and training in palliative care has been designed by the partner organisations of the Paletti project (Karelia UAS, PKKY and PKSSK). The cooperation during the project has helped the partners distribute their work and tasks better. Apparently, there is no similar model elsewhere in Finland where two educational establishments and a special health care unit jointly plan and implement continuing education and training.

The strength of the model is that it is need-based and systematically followed. Information is regularly collected through needs analyses and training feedback, which gives the members of the working group a possibility to predict and plan the future training modules better. Prediction plays an important role in planning (Sivonen & Pouri 2014). However, it requires the members of the working group to be active in networking and to keenly follow-up of the development of palliative care at both national and international levels. The evaluation of the implemented training modules

is an essential part of the development process (STM 2003, STM 2004). Assessment and evaluation of continuing education and training in palliative care is one of the future challenges facing the working group. As an example, the feedback from the patients and population should become an integral part of the assessment process in the future.

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Appendix 1. Results of the literature review and guidelines presented in form of tables. Physiotherapy used as an example.

(See the article earlier in this publication: Kopponen, M. & Suhonen, L.: Physiotherapy in a Multidisciplinary Palliative Care Team)

Table 1. Guidelines for spinal cord compression, physiotherapy used as an example. (Käypä hoito -suositus 2012; Palliative Care Guidelines Plus 2008a Fraser Health 2006a; Greater Manchester & Cheshire Cancer Network 2011, 40; Yorkshire Cancer Network and North East Yorkshire and Humber Clinical Alliance 2012, 34).

SPINAL CORD COMPRESSION		
<p>General facts</p> <ul style="list-style-type: none"> » spinal cord compression appears in 5 % of metastatic cancers » caused by metastases » important to avoid additional damage » medical assessment by a doctor necessary » breast cancer, lung cancer, prostate cancer, renal cell carcinoma and myeloma » thoracic spine 70 %, lumbosacral spine 20 %, cervical spine 10 % » back pain » difficulty in walking, weakness in the motoric functions of limbs » numbness » weakness in the tonus of the voluntary anal sphincter » loss of bladder control 	<p>Individual physiotherapy</p> <ul style="list-style-type: none"> » bed rest position is not necessary if the patient has the ability to move without pain » moderate physiotherapy plan (the patient has impaired functional capacity or resilience) » walking » therapeutic group exercise if the patient's general condition is good e.g. at the early stage of the disease 	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » evaluation of functional capacity » evaluation of pain <p>Estimate of the need for assistive devices</p> <ul style="list-style-type: none"> » choice of assistive devices supporting the patient's functional capacity » choice of an orthosis (e.g. spinal orthosis), if needed <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses <p>Physiotherapy plan</p> <ul style="list-style-type: none"> » monitoring the effectiveness of exercises (changes in functional capacity and in pain) » changing the programme to meet the changing needs of the patient

(Kopponen, M & Suhonen, L: Physiotherapy in multidisciplinary palliative careteam.)

Table 2. Guidelines for gastro-intestinal symptoms, physiotherapy used as an example. (Käypä hoito -suositus 2012; Australian Palliative Residential Aged Care 2006, 10; Fraser Health 2006c; Janes 2013; Macleod et. al. 2012, 18).

NAUSEA, VOMITING		
<p>General facts</p> <ul style="list-style-type: none"> » about 30 % of incurably ill patients suffer from vomiting » about 60 % suffer from nausea » can be caused by several reasons, e.g. infection, increased intracranial pressure, gastric irritation or ulcer, constipation, medication, chemotherapy / radiotherapy, ascites, anxiety, cough and accumulation of phlegm, severe pain 	<p>Relaxation techniques</p> <ul style="list-style-type: none"> » alleviation of anxiety <p>Acupuncture</p> <p>Acupressure</p> <p>Electro-acupuncture</p> <p>Acupressure as a method of self-care</p>	<p>Physiotherapeutic examination</p> <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on relaxation exercises » giving guidance on exercises performed with the help of family members, personal assistants or nurses <p>Physical therapy</p> <ul style="list-style-type: none"> » acupuncture techniques require a specially trained physiotherapist <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving the patient or his/her family members, personal assistants or nurses guidance on acupressure
CONSTIPATION		
<p>General facts</p> <ul style="list-style-type: none"> » reduced frequency of defecation, less than three times a week » about half of palliative care patients suffer from constipation » more frequent among patients treated with opioids » pharmacological treatment with laxatives 	<p>Physical exercise and activity</p> <ul style="list-style-type: none"> » increased bowel function » high intensity is not necessary <p>Thermal care package</p> <ul style="list-style-type: none"> » increased bowel function <p>Abdominal massage</p> <ul style="list-style-type: none"> » increased bowel function 	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » evaluation of functional capacity <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on the use of a thermal care package » thermal care provided by the patient, his/her family members, personal assistants or nurses <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » physiotherapist can give family members and personal assistants guidance on simple massage <p>Physiotherapy plan</p> <ul style="list-style-type: none"> » monitoring the effectiveness of exercises » changing the programme to meet the changing needs of the patient » monitoring the effects of thermal care and abdominal massage on bowel function

(Kopponen, M & Suhonen, L: Physiotherapy in multidisciplinary palliative careteam.)

Table 3. Guidelines for lymphoedema, physiotherapy used as an example. (Australian Palliative Residential Aged Care 2006, 105; Macleod et. al. 2012, 44; Kokkinen 2012; Käypä hoito -suositus 2012; Palliative Care Guidelines Plus 2010c; Yorkshire Cancer Network and North East Yorkshire and Humber Clinical Alliance 2012, 39).

LYMPHOEDEMA		
General facts » appears in patients with a metastatic cancer » prevention of lymphatic circulation or hyperproteinemia, may appear together with venous oedema » when lymphatic circulation becomes obstructed, diuretics are no longer effective (Käypä hoito -suositus 2012)	Lymphatic massage » intensifies lymphatic circulation	Physiotherapeutic examination » evaluation of functional capacity » choice of an appropriate exercise method Manual therapy » efficient and effective lymphatic massage requires a specially trained physiotherapist » if no trained specialist in lymphatic massage is available, a physiotherapist can slightly alleviate the symptoms by simple manual compression
	Simple lymphatic massage	Physiotherapeutic counselling and guidance » most efficient and effective guidance is provided by a physiotherapist specialised in lymphatic massage » giving the patient guidance on massage performed by him/herself » giving guidance on massage performed with the help of family members and personal assistants » instructing the patient to make an appointment with a massage therapist in case of slight oedema
	Compression therapy (pneumatic compression therapy) » compression garments » compresses » elastic therapeutic tapes, i.e. kinesio tapes	» Compression garments, compresses and tapes can be included in the patient's medical supply, and the use of these supplies might be the responsibility of the nursing staff (under the guidance of a doctor) working in multidisciplinary teams.
	Compression therapy alongside with physical exercise » increases the efficiency of compression therapy Physical exercise » alleviates lymphatic oedema	Physiotherapeutic counselling and guidance » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses Physiotherapy plan » monitoring the effectiveness of exercises and/or treatment » changing the programme to meet the changing needs of the patient
	Lymphatic bandaging » alleviates lymphatic oedema	Other physiotherapeutic methods » therapy provided by a therapist specialised in lymphatic bandaging Physiotherapeutic counselling and guidance » giving nurses guidance on bandaging; guidance provided by a therapist specialised in lymphatic bandaging

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Table 4. Guidelines for fatigue, physiotherapy used as an example. (Australian Palliative Residential Aged Care 2006, 86 - 87; Fraser Health 2006d; Macleod et. al. 2012, 49; NHS Lanarkshire 2009, 29; Palliative Care Guidelines Plus 2008b; Scottish Intercollegiate Guidelines Network 2008, 10; Käypä hoito -suositus 2012).

FATIGUE		
Fatigue » commonly cancer-related (60-90 %) » undertreated » must be separated from other causes of exhaustion and tiredness (e.g. anaemia, metabolic disturbances, hypothyroidism, infections) Symptoms » decrease in the activity level » weakness » tiredness » sleepiness » lack of motivation » boredom » apathy » symptoms not alleviated after resting » the link between fatigue and depression/anxiety might be more significant than that between fatigue and an underlying disease » may also be associated with pain, boredom, sleep disorders and medication	Physical exercise » particularly useful with long-term immobility » useful for e.g. exhaustion caused by radiotherapy » slows down skeletal muscle loss in case of anorexia and cachexia caused by a disease » planned, moderate physical exercise still useful at the final stages of the disease	Physiotherapeutic examination » evaluation of functional capacity » choice of an appropriate exercise method Physiotherapeutic counselling and guidance » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses Physiotherapy plan » monitoring the effectiveness of exercises » changing the programme to meet the changing needs of the patient

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Table 5. Guidelines for respiratory symptoms, physiotherapy used as an example.

DYSPNOEA			
(Australian Palliative Residential Aged Care 2006, 11; Borda et.al. 2013, 84; Greater Manchester & Cheshire Cancer Network 2011, 22; Janes 2013; Jassal 2013, 20, 53; Kokkinen 2012; KNGF 2008, 9 - 11; Käypä hoito 2009; Macleod et. al. 2012, 37; Palliative Care Guidelines Plus 2004b; 2004c.)			
<p>General facts</p> <ul style="list-style-type: none"> » a very common and disturbing symptom <p>Caused by:</p> <ul style="list-style-type: none"> » airway obstruction » decrease in tidal volume » lung infiltration » circulatory problems » respiratory muscle weakness » mental reasons <p>Non-pharmacological methods are less effective in the treatment of dyspnoea at the final stages of one's life, but they can be used to supplement medication.</p>	<p>Breathing exercises</p> <ul style="list-style-type: none"> » making breathing more effective 	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » evaluation of functional capacity 	
	<p>Relaxation exercises</p> <ul style="list-style-type: none"> » alleviation of anxiety 	<p>Therapeutic exercises</p> <ul style="list-style-type: none"> » exercising functional capacity 	
	<p>Physical exercise</p> <ul style="list-style-type: none"> » muscle strength and muscle tone » aerobic training » assistive devices 		
	<p>Back pressure breathing</p> <ul style="list-style-type: none"> » blowing into a water bottle » PEP device 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on breathing and blowing techniques » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses 	
	<p>Adaptation techniques</p> <ul style="list-style-type: none"> » coping strategies » methods of self-care » the aim is that functional capacity corresponds to the strain 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » choice of an appropriate exercise method » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses 	
	<p>Vibration treatment</p> <ul style="list-style-type: none"> » phlegm removal » patting and vibration techniques 	<p>Physical therapy</p>	
	<p>Electrotherapies</p> <ul style="list-style-type: none"> » NMES » EMS 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » vibration treatment and electrotherapies are rarely used in Finland in the treatment of dyspnoea [Lehto, Toikkanen & Saarto 2011]. » an applied patting or vibration technique can be taught to be performed by family members, personal assistants or nurses 	
		<p>Physiotherapy plan</p> <ul style="list-style-type: none"> » monitoring the effectiveness of exercises » controlling the technique applied in the exercises 	

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Table 5. continues:

COUGH		
(Janes 2013; Jassal 2013, 18, 53; Kokkinen 2012; Greater Manchester & Cheshire Cancer Network 2011, 24; NHS Lanarkshire 2009, 19; Macleod ym. 2012, 39; Palliative Care Guidelines Plus 2004c).		
<p>General facts</p> <ul style="list-style-type: none"> » chronic obstructive pulmonary disease (COPD) » lung cancer » pulmonary fibrosis (Käypä hoito -suositus 2012) <p>Physiotherapy is particularly useful in the treatment of cough caused by an infection by removing phlegm and sputum.</p>	<p>Active breathing techniques</p> <p>Breathing exercises</p> <p>Relaxation exercises</p> <p>Physical exercise</p> <p>Postural drainage treatment</p> <p>Cough assist device</p> <p>Assistive devices</p>	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » evaluation of functional capacity » evaluation of respiratory functions » choice of an appropriate exercise method <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on breathing techniques and effective coughing » giving guidance on independent exercise » drawing up a physiotherapeutic exercise programme » giving guidance on exercises performed with the help of family members, personal assistants or nurses » giving guidance on the use of assistive devices <p>Estimate of the need for assistive devices</p> <ul style="list-style-type: none"> » choice of appropriate assistive devices to support the patient's functional capacity
DEATH RATTLE		
(Borda et. al. 2013, 84 - 85; Wee & Hillier 2 - 5; Käypä hoito -suositus 2012.)		
<p>General facts</p> <ul style="list-style-type: none"> » can result from a blockage caused by phlegm in the respiratory tract » no clear evidence on the effect of pharmacological treatment 	<p>Physiological methods</p> <ul style="list-style-type: none"> » postural management, removal of phlegm (suction) 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » the methods may include the same methods used previously for the treatment of cough with the same patient » e.g. postural management performed by family members, personal assistants and nurses » physiotherapist's consultation may only be required in exceptional cases

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Table 6: Guidelines for pain symptoms, physiotherapy used as an example (Australian Palliative Residential Aged Care 2006, 6, 11; Voltz & Borasio 1997, 2; Käypä hoito -suositus 2012; Yorkshire Cancer Network, North East Yorkshire & Humber Clinical Alliance 2012, 6, 11; Borda et. al. 2013, 14 - 15; Jassal 2013, 77, 79, 90; North of England Cancer Network 2012, 4, 12; PCGP 2010e; Scottish Intercollegiate Guidelines Network 2008, 41; NHS Lanarkshire 2009, 67; Vella-Brincat & Macleod 2012, 14).

PAIN		
<p>General facts</p> <ul style="list-style-type: none"> » pain is an integral part of several fatal diseases <p>Non-pharmacological pain management methods</p> <ul style="list-style-type: none"> » can be used as a support for pharmacological treatment » particularly useful for situations in which the best pharmacological treatment is not suitable for some reason, or the patient refuses pharmacological treatment » have usually a short-term effect, but patients consider them pleasant » can improve the control of life experienced by the patient and alleviate mental symptoms 	<p>Postural management</p> <ul style="list-style-type: none"> » alleviation of pain 	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » examination and evaluation of pain » evaluation of functional capacity <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » postural management performed by family members, personal assistants and nurses
	<p>Physical exercise</p> <ul style="list-style-type: none"> » alleviation of pain 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » drawing up a physiotherapeutic exercise programme » independent exercise or exercise performed with the help of family members, personal assistants or nurses <p>Physiotherapy plan</p> <ul style="list-style-type: none"> » monitoring the effectiveness of exercises » changing the programme to meet the changing needs of the patient
	<p>Cryotherapy</p> <ul style="list-style-type: none"> » particularly useful for tissue damage 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on the use of e.g. ice packs » performed by family members, personal assistants or nurses
	<p>Thermotherapy</p> <ul style="list-style-type: none"> » affects the tissue and can also release endogenous opioids and thus alleviate pain 	<p>Physical therapy</p> <ul style="list-style-type: none"> » thermal treatment with e.g. ultra sound (if not contraindicated) or thermal care package <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on the use of a thermal care package » performed by family members, personal assistants or nurses

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Table 6: Guidelines for pain symptoms, physiotherapy used as an example (Australian Palliative Residential Aged Care 2006, 6, 11; Voltz & Borasio 1997, 2; Käypä hoito -suositus 2012; Yorkshire Cancer Network, North East Yorkshire & Humber Clinical Alliance 2012, 6, 11; Borda et. al. 2013, 14 - 15; Jassal 2013, 77, 79, 90; North of England Cancer Network 2012, 4, 12; PCGP 2010e; Scottish Intercollegiate Guidelines Network 2008, 41; NHS Lanarkshire 2009, 67; Vella-Brincat & Macleod 2012, 14).

	<p>Relaxation techniques</p> <ul style="list-style-type: none"> » alleviation of pain 	<p>Physiotherapeutic counselling</p> <ul style="list-style-type: none"> » giving guidance on relaxation exercises » giving guidance on relaxation exercises performed with the help of family members, personal assistants or nurses
	<p>Electrotherapies</p> <ul style="list-style-type: none"> » TENS » TSE » alleviation of pain 	<p>Physical therapy</p> <ul style="list-style-type: none"> » performed by a physiotherapist <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » home care patients may borrow a TENS device for a certain period of time, if needed » therapy can be performed by the patient or his/her family members, personal assistants or nurses after the guidance
	<p>Acupuncture</p> <ul style="list-style-type: none"> » alleviation of pain 	<p>Physical therapy</p> <ul style="list-style-type: none"> » use of acupuncture requires a specially trained physiotherapist
	<p>Auriculotherapy</p> <ul style="list-style-type: none"> » alleviation of peripheral and neuropathic pain 	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » instructing the patient to contact a specialist in auriculotherapy
	<p>Sciatic nerve compression</p> <ul style="list-style-type: none"> » alleviation of pain <p>Massage</p> <ul style="list-style-type: none"> » alleviation of pain 	<p>Manual therapy</p> <ul style="list-style-type: none"> » compression treatment performed by a trained physiotherapist <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving guidance on compression techniques to be performed by family members, personal assistants or nurses » giving guidance on simple massage to be performed by family members and personal assistants » alternatively the patient can be instructed to make an appointment with a massage therapist

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Table 7. Guidelines for the symptoms of spasticity, physiotherapy used as an example. (Atula 2013; Fraser Health 2006e; Jassal 2013, 72; 91; Kassinen 2013; Palliative Care Guidelines Plus 2010a; 2010d; Australian Palliative Residential Aged Care 2006, 86 - 87; Borda et. al. 2013, 14 - 15; Scottish Intercollegiate Guidelines Network 2008, 41).

SPASTICITY			
General facts <ul style="list-style-type: none"> » symptom of muscle stiffness » does not necessarily require treatment » may even enable movement by supporting the limb with a weakened muscle strength » taking individual characteristics and needs into account, physiotherapy intervention may be necessary » physiotherapy can be used to prevent skin problems, alleviate contractures and prevent dislocation of joints » physiotherapy is also needed for straightening the posture, finding a good seating position and evaluating appropriate assistive devices 	Physical exercises <ul style="list-style-type: none"> » active » passive » exercises for the range of motion in joints 	Physiotherapeutic examination <ul style="list-style-type: none"> » evaluation of functional capacity Physiotherapeutic counselling and guidance <ul style="list-style-type: none"> » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses 	
	Assistive devices	Estimate of the need for assistive devices <ul style="list-style-type: none"> » choice of assistive devices needed in daily routines » choice of assistive devices supporting moving 	
	Orthoses	Estimate of the need for assistive devices <ul style="list-style-type: none"> » choice of an orthosis supporting moving 	
	Postural management <ul style="list-style-type: none"> » alleviation of spasticity » prevention of contractures 	Estimate of the need for assistive devices <ul style="list-style-type: none"> » choice of assistive devices supporting postural management Physiotherapeutic counselling and guidance <ul style="list-style-type: none"> » giving the patient guidance on performing postural management » giving family members, personal assistants or nurses guidance on performing postural management 	
	Counselling <ul style="list-style-type: none"> » posture » sitting position 	Therapeutic exercises <ul style="list-style-type: none"> » exercising functional capacity and moving Physiotherapeutic counselling and guidance <ul style="list-style-type: none"> » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses 	

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Table 7. Guidelines for the symptoms of spasticity, physiotherapy used as an example. (Atula 2013; Fraser Health 2006e; Jassal 2013, 72; 91; Kassinen 2013; Palliative Care Guidelines Plus 2010a; 2010d; Australian Palliative Residential Aged Care 2006, 86 - 87; Borda et. al. 2013, 14 - 15; Scottish Intercollegiate Guidelines Network 2008, 41).

	Breathing techniques <ul style="list-style-type: none"> » exercising accessory muscles of respiration and the diaphragm 	Physiotherapeutic counselling and guidance <ul style="list-style-type: none"> » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses
	Massage <ul style="list-style-type: none"> » alleviation of spasticity 	Physiotherapeutic counselling and guidance <ul style="list-style-type: none"> » giving guidance on simple massage to be performed by family members and personal assistants » alternatively the patient can be instructed to make an appointment with a massage therapist Physiotherapy plan <ul style="list-style-type: none"> » monitoring the effectiveness of exercises » changing the programme to meet the changing needs of the patient

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Table 8: Guidelines for mental symptoms, physiotherapy used as an example. (Australian Palliative Residential Aged Care 2006, 86 - 87; Borda et. al. 2013, 14 - 15; Jassal 2013, 91; Käypä hoito -suositus 2012; Scottish Intercollegiate Guidelines Network 2008, 41.)

ANXIETY		
<p>General facts</p> <ul style="list-style-type: none"> » can be a natural reaction to the approaching death » can also be a sign of some other disorder or symptom 	<p>Physical exercise</p> <ul style="list-style-type: none"> » alleviation of anxiety 	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » evaluation of functional capacity <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses <p>Physiotherapy plan</p> <ul style="list-style-type: none"> » monitoring the effectiveness of exercises » changing the programme to meet the changing needs of the patient
INSOMNIA		
<p>General facts</p> <ul style="list-style-type: none"> » feeling of poor sleep » difficulty in staying asleep » difficulty in falling asleep » reduces one's functional capacity » irritability » sleepiness in daytime » lack of concentration » fatigue syndrome 	<p>Physical exercise</p> <ul style="list-style-type: none"> » makes it easier to fall asleep and stay asleep » helps in managing sleeping disorders associated with e.g. cancer 	<p>Physiotherapeutic examination</p> <ul style="list-style-type: none"> » evaluation of functional capacity <p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » drawing up a physiotherapeutic exercise programme » giving guidance on independent exercise » giving guidance on exercises performed with the help of family members, personal assistants or nurses
	<p>Relaxation techniques</p> <p>Relaxing massage</p>	<p>Physiotherapeutic counselling and guidance</p> <ul style="list-style-type: none"> » giving the patient guidance on relaxation exercises » giving guidance on exercises performed with the help of family members, personal assistants or nurses » giving guidance on simple massage to be performed by family members and personal assistants » alternatively the patient can be instructed to make an appointment with a massage therapist <p>Physiotherapy plan</p> <ul style="list-style-type: none"> » monitoring the effectiveness of exercises » changing the programme to meet the changing needs of the patient

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The articles in this publication describe the development work and the results of this project from different aspects. The authors include project partners, teachers and students. The articles focus on the implementation of good palliative and end-of-life care as multiprofessional cooperation by e.g. presenting the operational models developed during the project, describing the developed practices that aim at strengthening the competence in palliative and end-of-life care, and introducing good environments for end-of-life care.

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