Education as a cornerstone, how to ensure competence?

Minna Hökkä

NursEduPal @ IMPACT

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Nothing to declare

One of the writers of the guideline of the support for the closest-one

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- Diakonia University of Applied Sciences
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- Wellbeing Services County of North Ostrobothnia
  - » Project manager, FinPall-project
- Finnish palliative care research network
  - » Board member
- European Association for Palliative care
  - » Board member, member in the Board Executive Committee, secretary

Why are we speaking about palliative care?

- The need for palliative care is immense, when the population is ageing, and the incidence of non-communicable diseases is growing (and now Covid -19).
- The need of palliative care is still increasing in the future since it is expected to double by 2060.

- -> The need of professionals with good skills in palliative care is increasing.

Connor SR (2020). Global atlas of palliative care (2nd ed.). Retrieved from http://www.thewhpca.org/resources/item/global-atlas-of-palliative-care-2nd-ed-2020.

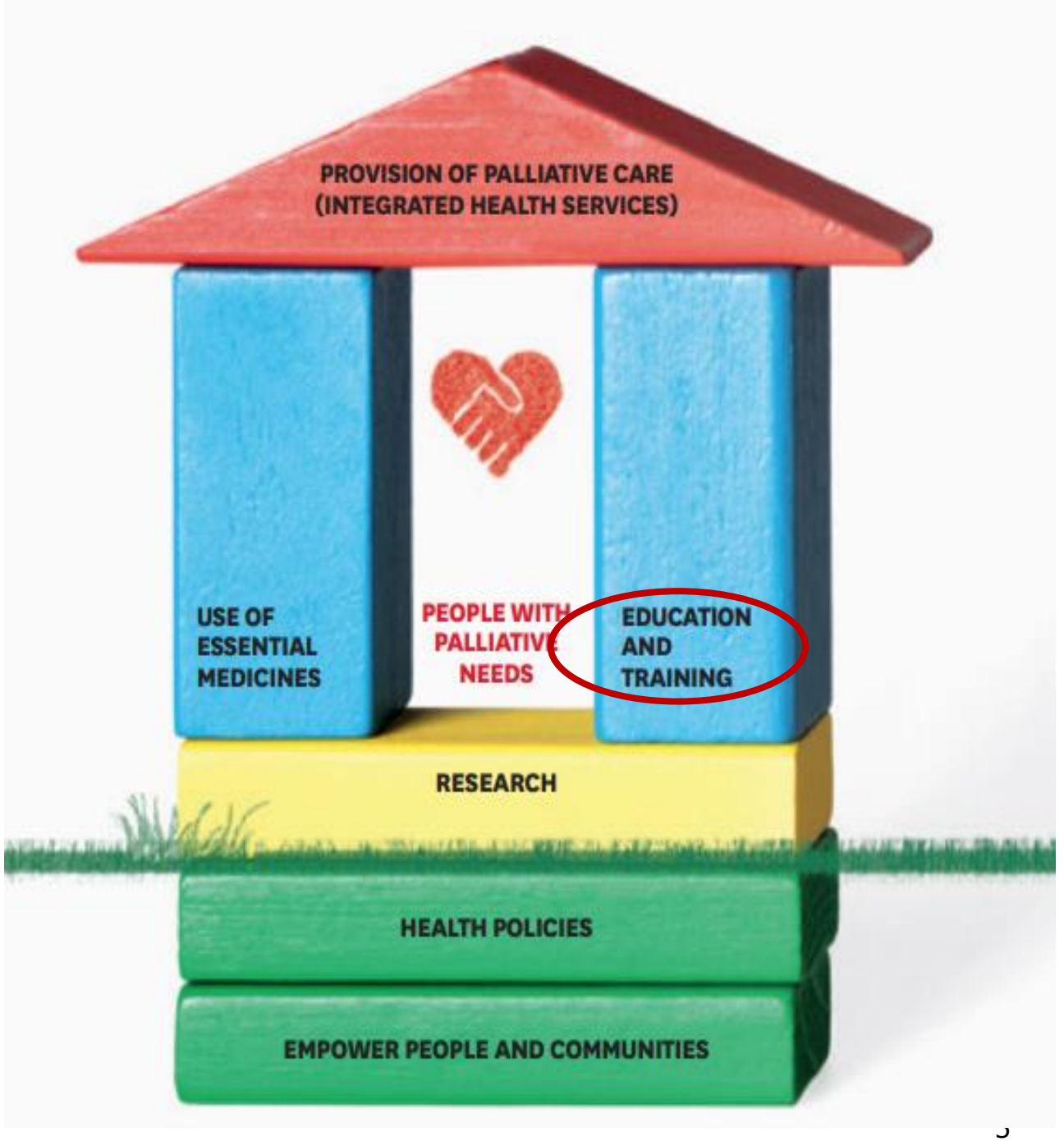
Why is education and competencies important?

- Lack of training and awareness of palliative care among health care professionals is a major barrier to improve PC access.

World Health Organization

- Insufficient palliative care education has been identified as a major barrier to the development of palliative care. (Centeno et al. 2017)

Conceptual model for palliative care development

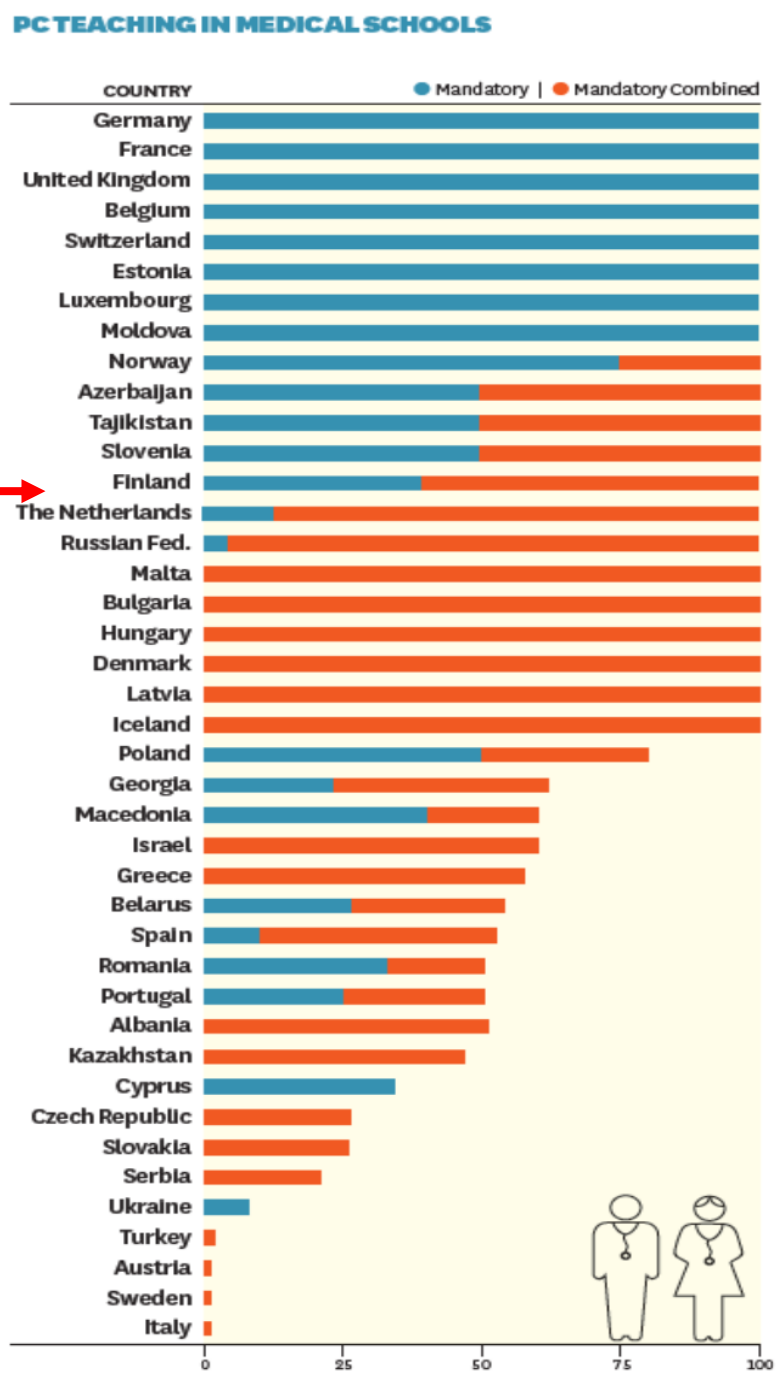


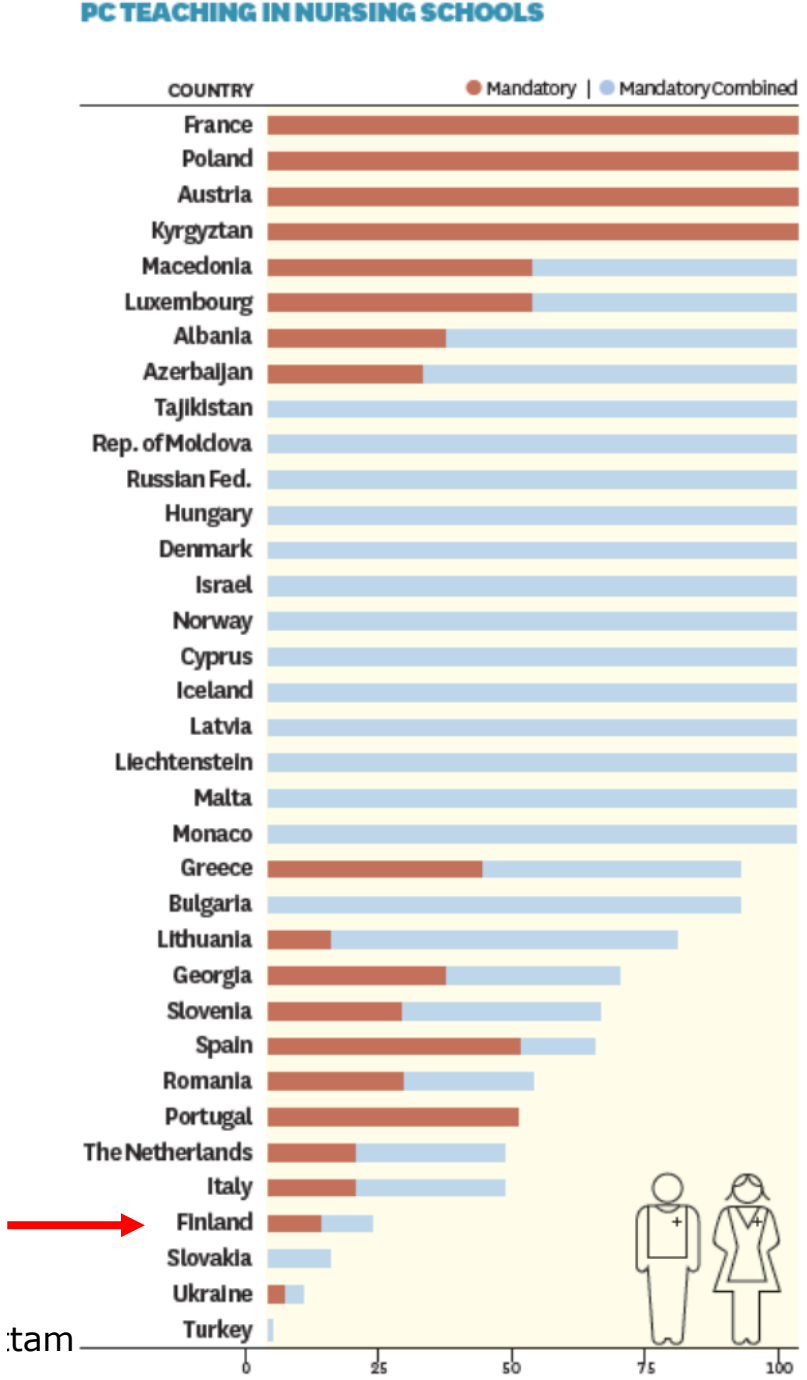
Assessing the development of palliative care worldwide: a set of actionable indicators. Geneva: WHO; 2021. Licence: CC BY-NC-SA 3.0 IGO.

Nurses role in palliative care

- A systematic review of palliative care health services found more support for the role of nurses than any other discipline. (Lorenz, K.A., et al., 2008)
- As the largest workforce, nurses are in a strategic position to influence the quality of palliative care delivery across all settings and levels. More and more in primary care, nursing homes, homes, hospitals etc.
- Nurses who provide palliative care need a wide range of competencies.

EAPC Atlas of Palliative Care in Europe 24.5.2019





Finland – 2019

Medical Schools teaching PC

5/5

40%
offering specific mandatory PC course

Nursing Schools teaching PC

4/21

10%
offering specific mandatory PC course

Professorship in PC at medical schools

1

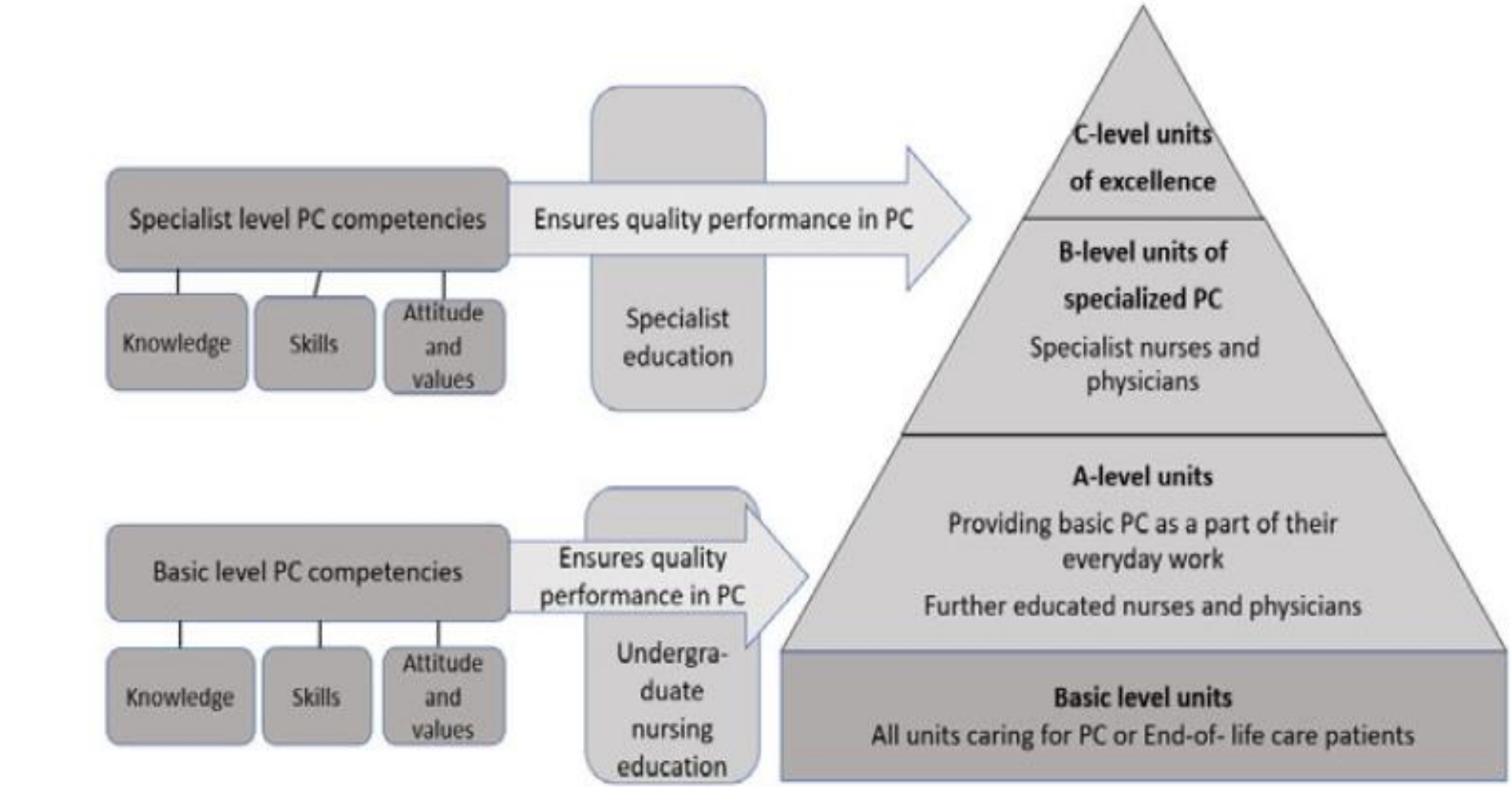
1
Full Professors

EAPC Atlas of Palliative Care in Europe 2019

WHAT HAVE BEEN DONE TO DEVELOPE PALLIATIVE CARE IN FINLAND?

- A project funded by the Ministry of Social Affairs and Health 2018-2020: Recommendation on the provision and improvement of palliative care services -> includes also recommendations to ensure nurses and physicians competences and education

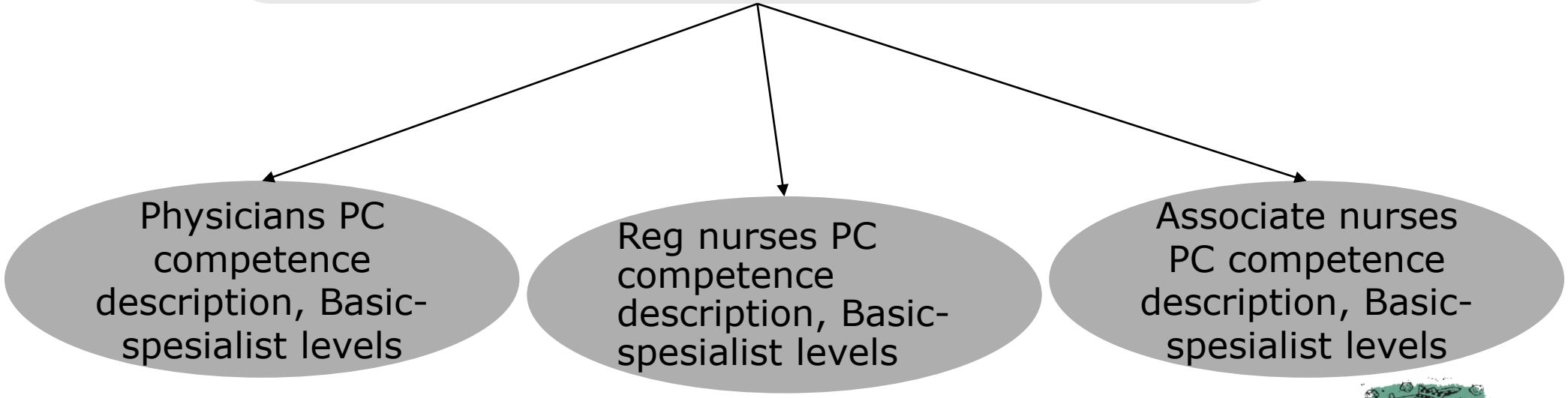
- A project funded by the Ministry of Education and Culture, EduPal 2018-2021, aims to develop competence descriptions for nurses and physicians, develop curriculum recommendation for undergraduate and specialist education. -> Innovative teaching methods based on evidence



PC=Palliative care

Competence descriptions

Data:
Professionals (n=222)
Patients and closest ones (n=41)
Associations (n=24)
Systematic review



Opetus- ja kulttuuri-ministeriö

Hökkä M, Martins Pereira S, Pölkki T, Kyngäs H, Hernández-Marrero P. Nursing competencies across different levels of palliative care provision: A systematic integrative review with thematic synthesis. Palliative Medicine. 2020;34(7):851–870.

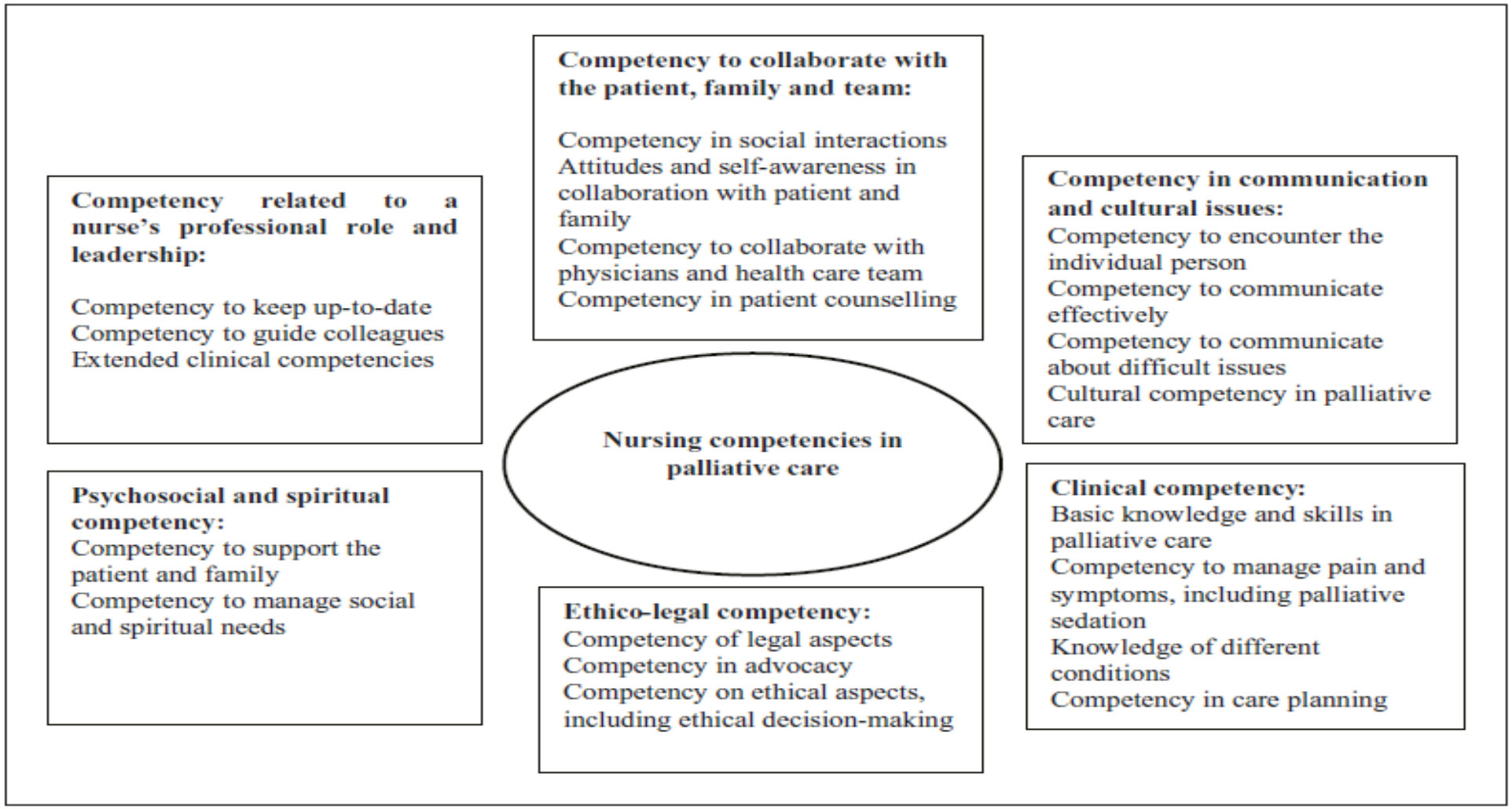


Figure 2. Nursing competencies in palliative care.

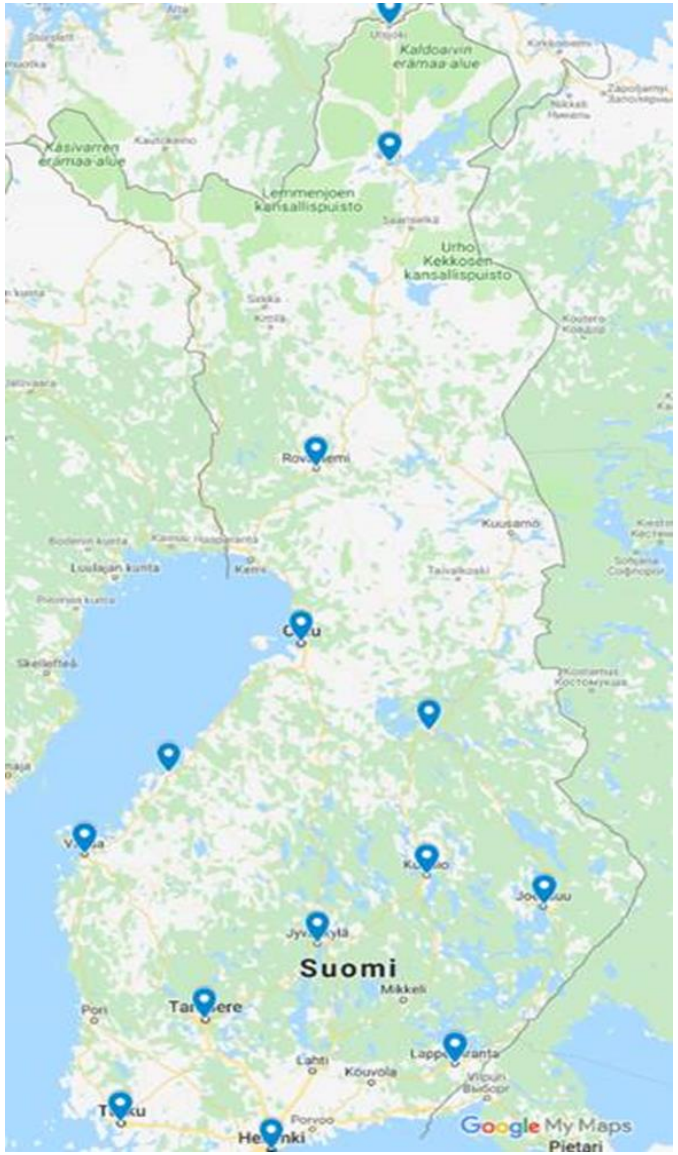
What did the systematic review tell us?

- A total of 7454 articles were retrieved, 21 articles were included in the analysis.
- Nurses need a wide range of competencies to provide quality palliative care.
- **Barely no studies focused on which competencies are relevant to a specific level of palliative care provision.**

  -> More research needed

Competencies in different levels of palliative care provision

- 222 professionals around the country (nurses, physicians, nurse managers etc.)



1. Hökkä M, Melender H-L, Lehto J, Kaakinen P.
Palliative nursing competencies required for different levels of palliative care provision: a qualitative analysis of healthcare professionals' perspectives. J Palliat Med. 2021. https://www.liebertpub.com/doi/10.1089/jpm.2020.0632
2. Melender H-L., Hökkä M., Saarto T. & Lehto J.
The required competencies of physicians within palliative care from the perspectives of multi-professional expert groups: a qualitative study. BMC Palliative Care. 2020; 19:65. https://rdcu.be/b341q

Table 3. Nursing Competencies Required for Basic Palliative Care Level with the Number of Codes Included in the Main Categories and Subcategories (*f*)

Main category	*Subcategory*
(1) Competence in managing the most common symptoms (*f*=75)	(1) Assessing the patient's symptoms and defining the need for treatment (*f*=30)
	(2) Mastering of pharmacological and nonpharmacological methods of symptom management (*f*=17)
	(3) Implementation of symptom relieving care (*f*=10)
	(4) Assessing physical symptoms and defining the need for treatment (*f*=7)
	(5) Basics of symptom management (*f*=7)
	(6) Assessing psychosocial symptoms and defining the need for treatment (*f*=4)
(2) Competence in supporting the patient and her/his closest ones (*f*=74)	(7) Identification of the need for, and implementation of, psychosocial support (*f*=20)
	(8) Supporting the closest ones in palliative care (*f*=14)
	(9) Maintenance of hope (*f*=10)
	(10) Provision of psychological support (*f*=10)
	(11) Coordination of spiritual support (*f*=7)
	(12) Involving the closest ones in care (*f*=6)
	(13) Supporting the patient in palliative care (*f*=4)
	(14) Utilization of multiprofessional support (*f*=3)
(3) Competence in basics of holistic palliative care (*f*=68)	(15) Understanding concepts and guidelines of palliative care (*f*=15)
	(16) Basic nursing care as a part of palliative nursing (*f*=13)
	(17) Palliative care of different patient groups (*f*=12)
	(18) Assessment of the need for palliative care (*f*=11)
	(19) Holistic palliative nursing (*f*=9)
	(20) Addressing oral, skin, position and mobility issues in palliative care (*f*=6)
	(21) Nutrition as a part of palliative nursing (*f*=2)
(4) Competence in encountering the patient (*f*=51)	(22) Encounters with persons during palliative nursing (*f*=40)
	(23) Presence as a part of palliative nursing (*f*=13)
	(28) Nonpharmacological methods of pain management (*f*=7)
	(29) Basics of pain management (*f*=5)
(5) Competence of pain management and nursing care of patients in pain	(25) Assessment of pain (*f*=15)
	(26) Pharmacological methods of pain management (*f*=15)
	(27) Implementation of pain management and nursing care of patients in pain (*f*=9)

(18) Competence in maintaining expertise and taking care of own well-being at work ($f = 34^{d}$)	(88) Active self-development ($f = 5^{c}$) (89) Postgraduate education ($f = 6^{c}$) (90) Strong clinical know-how ($f = 4^{c}$) (91) Autonomous decision-making and expertise ($f = 10^{c}$) (92) Critical thinking and reflection ($f = 2^{c}$) (93) Recognition of one's own limits and acceptance of support ($f = 7^{c}$)
(19) Advanced symptom management in nursing care of patients in palliative care ($f = 26^{d}$)	(94) Extensive know-how in symptom management ($f = 4^{c}$) (95) Assessment and management of advanced symptoms ($f = 4^{c}$) (96) Palliative sedation and the issues related to it ($f = 6^{c}$) (97) Special techniques for the management of symptoms ($f = 6^{c}$) (98) Autonomous management of symptoms ($f = 1^{c}$) (99) Acute situations in palliative care ($f = 5^{c}$)
(20) Teaching, development and research competence in palliative care ($f = 20^{d}$) (21) Extensive competence in palliative nursing care of special groups ($f = 20^{d}$)	(100) Educating about palliative care ($f = 12^{c}$) (101) Development of palliative care ($f = 6^{c}$) (102) Researching phenomena linked to palliative care ($f = 2^{c}$) (103) Palliative care for different special groups ($f = 10^{c}$) (104) Palliative care for children and adolescents ($f = 7^{c}$) (105) Palliative care for mentally retarded persons ($f = 2^{c}$) (106) Palliative care for lonely persons ($f = 1^{c}$)
(22) Competence in advanced support to patient in palliative care, and her/his closest ones ($f = 19^{d}$) (23) Extensive competence in coordination of palliative care ($f = 19^{d}$)	(107) Assessment of the need for social support in patients and their closest ones, along with the provision of support ($f = 6^{c}$) (108) Provision of support for grief work ($f = 5^{c}$) (109) Advanced psychosocial support ($f = 3^{c}$) (110) Specialized support for families with children ($f = 5^{c}$) (111) Collaboration with the third sector ($f = 1^{c}$) (112) Coordination of the patient's care chain and ensuring the continuity of patient's care ($f = 10^{c}$)

(*continued*)

What do the patients want?

- *” To encounter the patient and family is important” (v60)*
- *” To have the skill for empathic encounter” (v62)*
- *”You should not complain you hurry to the patient” (v58)*
- *” Ideally, nurses have the ability to interpret what physicians say (patients are often unclear what palliative care means)” (v60)*
- *” Important to have competence in pain management” (v57)*
- *” Skills to educate the closest ones regardin pain medication and other medications.” (v46)*
- *” Skills to educate where I can find more information and to inform of all the help I can recieve” (v62)*
- *” Skills to encounter the disstressed patient” (v69)*
- *”Be the person who makes me feel safe on my last voyage” (v44)*

Vihelä M, Hökkä M, Kaakinen P. Potilaiden ja läheisten kokemukset sairaanhoitajan palliatiivisen hoidon ja saattohoidon osaamista. Hoitotiede-lehti, 2020; 32(4): 275–284.

What do stakeholders think and what is the future needs?

Mäenpää P, Lamminmäki A, Kaakinen P, Hökkä M. 2021. **Experiences of the patients and loved ones of physicians competencies of palliative care.** (Potilaiden ja läheisten kokemuksia lääkärien palliatiivisen hoidon ja saattohoidon osaamisesta) Sosiaalilääketieteellinen aikakauslehti. 58: 181-189.

Suikkala, A., Tohmola, A., Rahko E.K., & Hökkä, M.2021. **Future palliative competence needs – a qualitative study of physicians' and registered nurses' views.** BMC Medical Education. Accepted for publication 2.9.2021

Nursing students views of palliative care education (Hökkä et al 2022. BMC Palliative Care)

DEVELOPMENT NEEDS AND VIEWS OF PC EDUCATION (f=524)

THE NEED TO DEVELOP PC EDUCATION (f=414)
More PC education in general (f=270)
More comprehensive and coherent education (f=109)
Integrate PC clinical practice into the studies (f=35)

MEANING OF PC AND ITS EDUCATION (f=110)
Importance of PC education (f=55)
The meaning of PC (f=33)
The importance of PC in nursing profession (f=22)

PREFERRED TYPES OF PC EDUCATION (f=1379)

TEACHING CONTENTS IN PC EDUCATION (f=905)
Encounters in PC (f=162)
Support in PC (f=123)
Holistic pain management (f=94)
Communication and interaction in PC (f=73)
Cultural issues in PC (f=61)
The basics of PC (f=56)
Special principles of pharmacology in PC (f=54)
Advanced care planning, decision making in PC (f=48)
Education of end-of-life care (f=31)
Ethical and legal issues in PC (f=31)
Somatic symptom management in PC (f=30)
Existential issues in PC(f=26)
Self-awareness in PC (f=25)
PC to different patient groups (f=23)
Psychological symptom management in PC (f=21)
Non-pharmacological care in PC (f=20)
PC in different settings (f=17)
Multidisciplinary teamwork (f=10)

TEACHING METHODS FOR LEARNING PC (f=393)
Patient cases and collaboration with working field in teaching (f=146)
Multidimensional teaching methods (f=88)
Experiences and exposure-based teaching (f=49)
Learning from discussions about PC (f=46)
Skills labs and simulation pedagogy in PC education (f=40)
Multidisciplinary teaching and learning (f=24)

PLACEMENT OF PC STUDIES (f=81)

Integrated and unifying PC education in the curriculum (f=35)
Preparatory teaching from the first semesters (f=29)
In-depth learning in the final semesters (f=17)

FACTORS THAT PROMOTE OR HINDER PC LEARNING (f=401)

FACTORS FACILITATING PC LEARNING (f=66)
Previous clinical experience about PC (f=31)
Obtained formal education (f=25)
Intrinsic motivation to learn about PC (f=10)

BARRIERS TO PC LEARNING *(f=335)*
Insufficient amount of education (f=119)
Insecurity of own performance in PC (f=56)
Discrepancy between teaching methods (f=43)
Insufficient structure of education (f=37)
Shortcomings of competences and clinical learning (f=35)
Impractical content of the education (f=27)
Teacher's insufficient competences of the subject (f=18)

PC= Palliative care
(f)= amount of codes (reduced expressions) in the category

The effect of teaching methods in palliative care education for undergraduate nursing and medical students: a systematic review

Minna Hökkä, Mira Rajala, Pirjo Kaakinen, Juho T. Lehto and Hanna-Mari Pesonen

International Journal of Palliative Nursing June 2022 Vol 28, No 6

- Findings: Simulations, lectures, films and a humanistic approach all had a positive effect on students' attitudes to care for a dying person. Problem-based learning, simulations and elective courses increased students' knowledge of palliative care. Game interventions in education decreased students' fear of death, while communication with dying patients and relatives became easier.

How to ensure competence?

Ministry of helth and welfare recommendation f for palliative care

C-level	**All nurses and physician have a specialist education in palliative care** **Clinical expert nurse with master degree education** Education plan for continuous education Collaboration with universities and other education to provide PC education and research
B-level	**Most nurses and physician have a specialist education in palliative care** Education plan for continuous education Coordination of education for other levels in the area
A-level	**Named physician and nurse in the unit who have education in palliative care** Education plan for continuous education
Basic level	Basic competence of palliative care achieved in education Systematic orientation for new staff Education plan for continuous education

Building a clinical career pathway for nurses (will be published 2024)

Curriculum recommendations

Data:

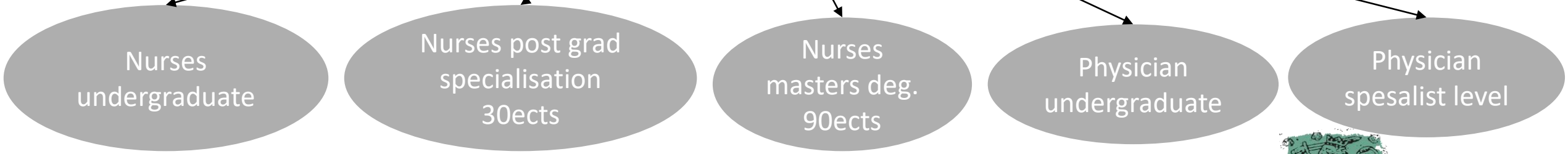
Basic-and specialist level competence descriptions

Students Nursing (n=1331), Medicine (n=502)

Professionals: Specialist physicians (n=62), Specialist nurses (n=122)

EAPC recommendations

Four professors in palliative medicine (clinical-teacher in the fifth university)



Included in the national framework

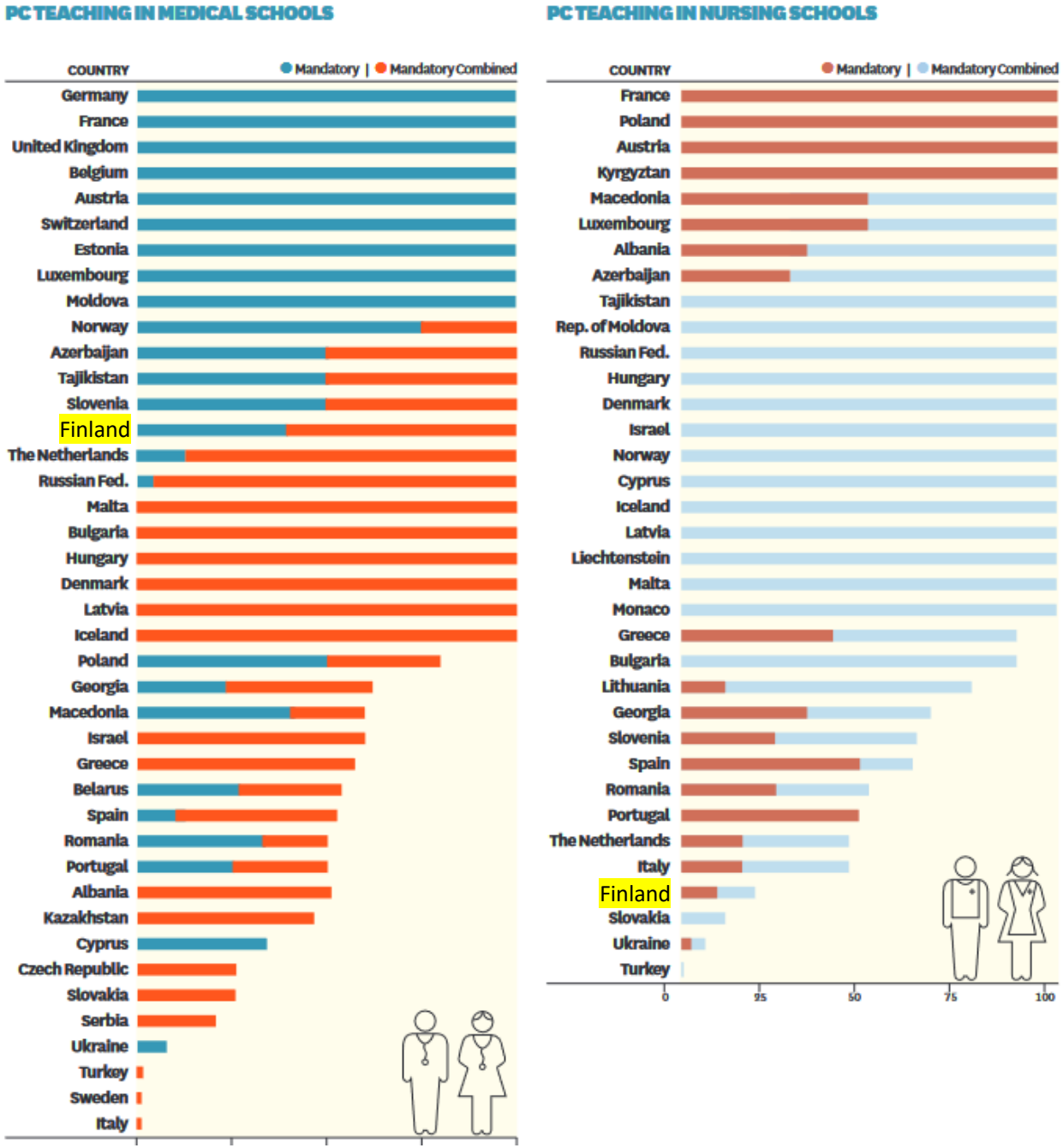
National curriculum. About 600 graduated specialists

National curriculum, about 70 graduates advanced practice nurses

Included as mandatory in all universities

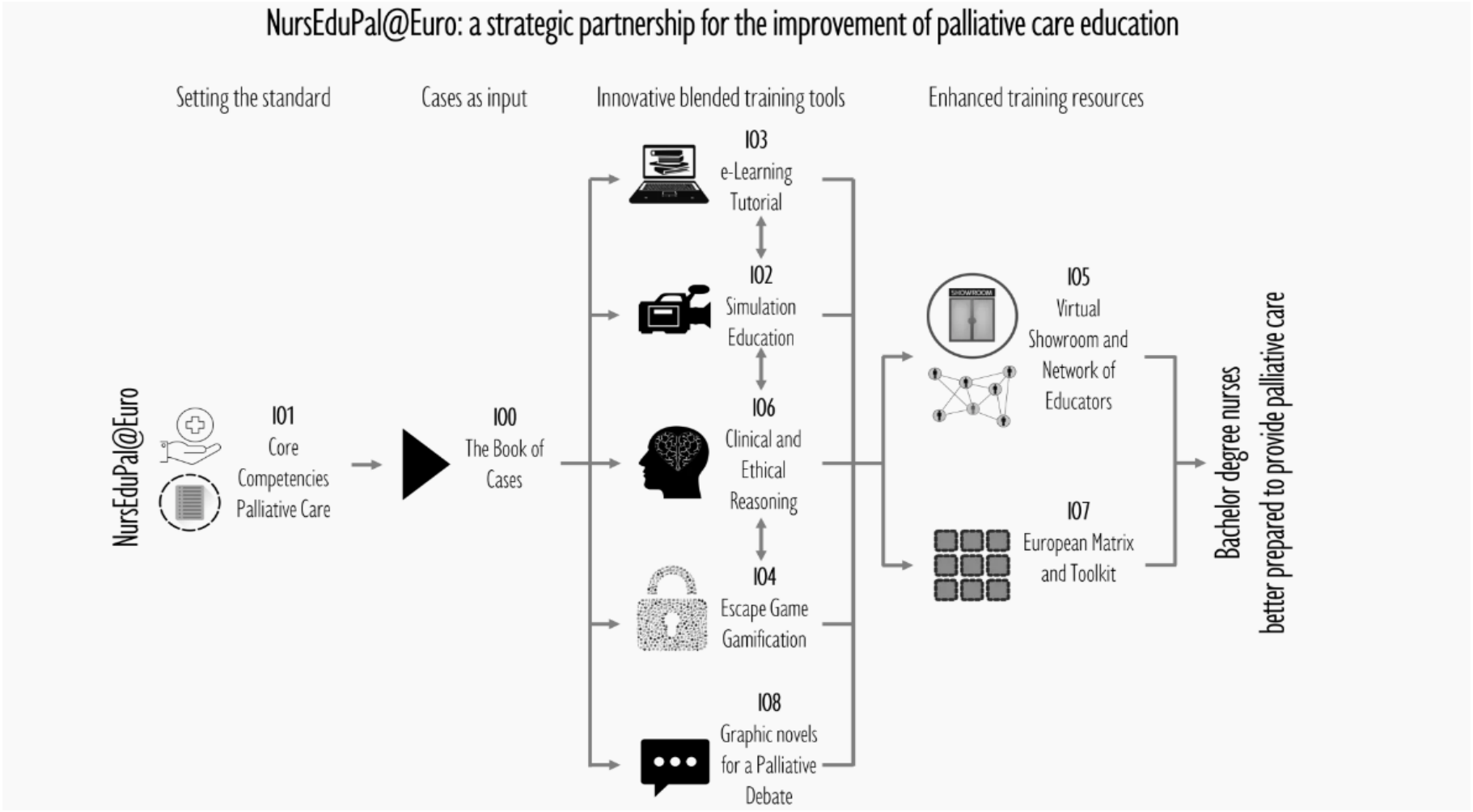
Opetus- ja kulttuuri-ministeriö

Palliative care education across Europe



EAPC Atlas of Palliative Care in Europe 2019

Development of education in Europe



Core Palliative Care Competencies for Undergraduate Nursing Education: International Multisite Research Using Online Nominal Group Technique

Minna Hökkä, PhD, RN[1], Teija Ravelin, PhD, RN[2], Veerle Coupez, MSc, RN[3], Danny Vereecke, PhD[3], Joanne Brennan, BSc Physiotherapy[4], Teodora Mathe, PhD, MSc, APRN[5,6], Cornelia Brandstötter, MA[7], Piret Paal, PhD, MA, BA[7,8], Daniela Elena Spanu, PhD, RN[5], and Nicoleta Mitrea, PhD, MSc, APRN, FAAN[5,6]

uring Undergraduate Nursing

Analytical themes	Descriptive themes
Competence in the characteristics of palliative care	The philosophy of palliative care
	The purpose of palliative care
	Palliative care in different patient groups
Competence in decision-making and enabling palliative care	Organizing palliative care
	Critical evidence-based thinking and decision-making in palliative care
	Advanced care planning in palliative care
	Advocacy in palliative care
Symptom management competence in palliative care	Identifying and assessing symptoms in the context of palliative care
	Principles of symptom control in palliative care
	Symptom management in palliative care
	Non-pharmacological symptom management in palliative care
	Pharmacological symptom management in palliative care
	Pain management in palliative care
Competence in holistic support in palliative care	Responsiveness and supportiveness to psychosocial needs in palliative care
	Person-centred supporting when working with palliative patients and those most important to them
	Culturally sensitive supporting in palliative care
	Grief and supporting in bereavement during the different phases of the palliative care process
Active person-and family-centred communication competence in palliative care	Open and active verbal and non-verbal communication in palliative care
	Open and active listening in palliative care
	Discussion of difficult topics in palliative care
	The importance of being present in palliative care
	Open-minded and dignified encountering in palliative care
	Responsive appropriate interaction in palliative care
	Encounters with the closest ones to patients in palliative care
	Communication, and interaction with those most important to patients' in palliative care
Competence in empathy in palliative care	Empathy in palliative care
	Empathic communication in palliative care
Spiritual competence in palliative care	Meaning of spirituality in the context of palliative care and its importance to patients
	Assessment of the spiritual needs of the patients in palliative care
	Support patients with spiritual needs in the context of palliative care
	Openness and confidence toward spiritual, religious and existential issues in palliative care
Competence in ethical and legal issues in palliative care	Ethical issues in palliative care and end of life situations
	Working according to moral and ethical values in palliative care
	Legislation in palliative care
Teamwork competence in palliative care	Interdisciplinarity in palliative care
	Cooperation in interdisciplinary palliative care team
	Active, pro-active and confident communication with other disciplines involved in palliative care
	Teamwork in palliative care
Self-awareness and self-reflection competence in palliative care	Recognizing and dealing with own emotions arising in palliative care
	Reflecting own emotions of death and loss
	Self-reflection concerning values and own actions in palliative care
	Openness to personal and professional growth

CODE-YAA

WG 1: Gold Standard

Defining quality indicators for Palliative Care Education – Testing the CODE-YAA tool

WG 2: Culture, Language & Diversity

Translation of the CODE-YAA tool – Preparing glossary for translation – Missions to showcase innovative teaching methods

WG 3: Research Coordination, Methods & Impact Analysis

Data analysis for scientific & public dissemination – Promote uptake of CODE-YAA results to relevant policy-makers and member states

WG 4: Capacity Building, Leadership & Ethics

Leadership Education Programme – Ethics Programme in Palliative Care – Mentorship Programme

WG 5: Global Policy & Advocacy

Advocacy & Policy Training – Scientific & public dissemination for advocacy and best practice

WG 6: Communication & Dissemination

Calls & Actions – Stakeholder communication – Dissemination congresses

PIRET PAAL

ACTION CHAIR & GRANT HOLDER
SCIENTIFIC REPRESENTATIVE

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ACTION VICE-CHAIR

STEPHEN MASON

LEAD WORKING GROUP 1

PHILIP LARKIN

LEAD WORKING GROUP 2

GIL GOLDZWEIG

LEAD WORKING GROUP 3

VILMA TRIPODORO

LEAD WORKING GROUP 4

TANIA PASTRANA

LEAD WORKING GROUP 5

GUILLAUME ECONOMOS

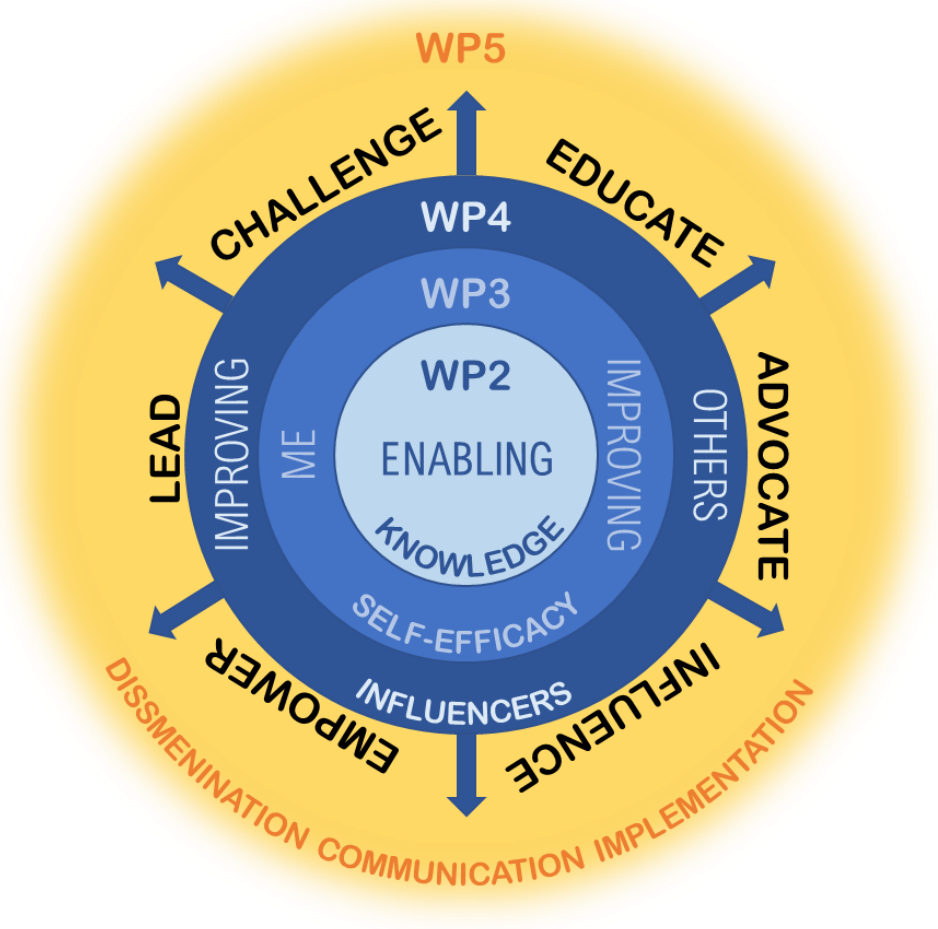
LEAD WORKING GROUP 6

Connecting higher education and practice for collaborative learning in nursing leadership in palliative care

NursEduPal @ IMPACT

Vision

By empowering nurses, we are building better palliative care



https://palliativeprojects.eu/nursedupal/

To create better education, we need to hear the nurse's voice

NursEduPal@Impact

Survey QR Codes

9 languages

Flemish

The NursEduPal@IMPACT team

howest hogeschool


Veerle Coupez


Danny Vereecke


Heidi Defloor

Diak


Minna Hökkä


Arja Suikkala


Lena Segler-Heikkilä

HOSPICE CASA SPERANȚEI
PREȚUIM FIECARE CLIPĂ DE VIAȚĂ


Nicoleta Mitrea


Andreea Szabo


Camelia Ancuta


Teodora Mathe


Otilia Catoiu

EAPC VZW


Cathy Payne


Patricia White


Guillermo Palacios

The definition of palliative care

- Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

World Health Organization

  - **Who are the closest ones ?**

Why is it important to support the closest-ones?

- A severe illness has always social aspects. It effects patients closest-ones in many ways during the illness trajectory.
- During palliative care, closest ones must be ensured the opportunity to participate in the patient's care. (Ministry of Social Affairs and Health, 2017)
- After the death of a child, continued support for family members should be ensured and the family should receive individual support and guidance in their grieving process. (Ministry of Social Affairs and Health, 2019)
- Grief increases the risk of mortality from natural (heart disease, MS, cancer) and unnatural (suicide) causes (Li 2002;2003;2005)
- Increased risk of mental illness; increased insomnia, suicidal thoughts, depression (Stroebe et al. 2007)

Evidence based guideline

- The purpose of the guideline is to guide the professionals in their evidence-based practice.
- The research method was a systematic search for information and synthesis of the achieved results. The searches was carried out in CINAHL, Medline, Medic, Cochrane, PsycInfo and Scopus databases.
- The evidence-based recommendation included systematic reviews and other reviews relevant to the subject area, as well as original studies, which quality was assessed as sufficiently good according to the JBI critical evaluation checklists.
- The studies had to deal with the encounter and/or support of the closest-ones of a patient in palliative care or end-of-life care from the perspective of the closest ones.

Nursing Research Foundation

a national, non-profit research and development organization.

Guidelines to encounter and support the closest-ones of both adult and child patients

- Participation in decision-making
- Presence and participation of closest ones in the patient's care
- Encountering closest ones
- Encountering and caring for the patient as part of the support of closest ones
- Providing information for closest ones
- A peaceful environment and privacy
- Practical support for closest ones
- Multi-professional, spiritual and existential support for closest ones
- Continuous support after death and peer support
- Consideration of the closest-ones holistic and comprehensive need for support
- Ensuring sufficient number, persistence and availability of social and healthcare professionals.

Participation in decision-making

- Make it possible for loved ones to be involved and consulted in decision-making situations
  - Closest-ones want to be involved in the palliative or end-of-life care of a person in palliative or end-of-life care or in the decision-making process related to the care of the patient. (A)
- Provide adequate information to the family in decision-making situations
- Calm down situations where the closest-ones are involved in the decision-making process
- Discuss their role in palliative or hospice care and in decision-making about end-of-life-care with the closest-ones
  - People close to a patient in palliative and end-of-life care may not be aware of their rights and responsibilities in relation to end-of-life care (B)

Presence and participation of closest ones in the patient's care

- Provide enough guidance to the closest- ones of the patient's care
  - loved ones want guidance on the care of patients in palliative care, considering their individual needs (A).
- Enable closest-ones to be involved in the palliative and end-of-life care of the patient
- Enable the presence of closest ones with the patient in all situations, if the patient and closest-ones so wish
  - being with the dying parent helps the child to cope after the death of the parent (A)
- Enable closest-ones to be involved in the care of the deceased

Encountering closest ones

- Take into account and treat the closest-ones with respect
  - Closest-ones feel that it is important that their role and expertise to be taken into account in palliative and end-of-life care (A)
- Pay attention to encountering and interacting with the closest-ones
- In encounters with closest-ones of the patients in palliative and end-of-life care, take into account the need for them to communicate with health professionals
  - Closest- ones feel that it is important to be heard and to discuss hope and preparing for the future (A)
- Encounter the closest-ones in a non-urgent manner, responding to their needs

Encountering and caring for the patient as part of the support of closest ones

- Treat patients in palliative and end- of –life care with individuality, dignity and respect for their wishes
  - loved ones feel that it is important the patient is treated compassionately, individually and that their wishes are respected (A)
  - the relatives apparently feel that treating the patient with dignity increases their confidence in the treatment and empowers the relatives (B)
- Ensure that the patient receives high-quality care that is appropriate to their needs and symptoms
  - untreated symptoms in a palliative care patient can increase the anxiety of loved ones.(C)

Providing information for closest ones

- Provide comprehensive, understandable and varied information to the closest-ones
  - Closest-ones to a patient in palliative and end-of-life care want to be informed about the patient's illness, situation and prognosis (A)
  - Closest-ones to a patient in palliative and end-of-life care want to be informed about death and the time after death (A)
  - Closest-ones to a patient in palliative or end-of-life care feel that receiving adequate and understandable information reduces their negative feelings (A)

A peaceful environment and privacy

- Enable a quiet space for the patient and closest-ones
  - A homely, private and peaceful environment contributes to the well-being of the closest-ones of patients in palliative or end-of-life care (A)

- Enable closest-ones to care for the patient at home
  - Enabling closest-ones to care for the patient at home may give closest-ones a sense of satisfaction when caring for a sick family member at home (C)
  - Parents may want to be able to choose where their child will receive end-of-life care. (C)

Practical support for closest ones

- Collect memories and enable loved ones to create memories of the dying or deceased
  - loved ones feel it is important to create memories of the last moments of a patient in end-of-life care (A)
- Arrange for help and support for loved ones in the care of a palliative or end-of-life care patient
- Help relatives to find social support
- Facilitate and contribute to the continuity of normal daily life in the families of terminally ill parent
  - children of terminally ill parent feel that the continuation of everyday life is important for their own well-being and for maintaining social relationships (A)
- Organize practical support for the relatives of patients in palliative and end-of-life care and refer them to the services they need,

Multi-professional, spiritual and existential support for closest ones

- Enable multidisciplinary support for closest-ones according to their needs
  - multidisciplinary support in palliative care increases the well-being, quality of life and satisfaction of closest-ones (A)

- Enable the closest-ones to patients in palliative and end-of-life care to discuss existential issues and offer them the possibility of spiritual support
  - The closest ones might need spiritual and existential support (B)

Continuous support after death and peer support

- Ensure continued support for closest-ones after the patient's death
  - a lack of support after the death of a loved one can leave them feeling helpless, invisible and isolated (C)
- Refer loved ones to peer support
  - Peer support is valued and perceived as important by closest-ones (A)

Consideration of the closest-ones holistic and comprehensive need for support

- Consider the need for support for all family members of a patient in palliative or end-of-life care
  - Palliative care and death affect all family members and their need for support (A)
- Provide support for the relatives of the palliative and end-of-life care patient
  - Emotional and psychological support is perceived as important by relatives (A)
  - Closest-ones apparently perceive a lack of emotional support as a cause of negative emotions. (B)

Ensuring sufficient number, persistence and availability of social and healthcare professionals.

- Ensure the competence of social and health professionals in palliative and end-of-life care
- Ensure an adequate number of social and health professionals for palliative and end-of-life care
  - the lack of sufficient numbers of professionals is apparently perceived by the people concerned as stressful and as reducing the quality of care (B)
- Ensure the commitment and retention of social and health professionals in palliative care
- Ensure consistent guidelines and regulations for patient care
- Ensure that closest-ones have possibility to contact, and that health and social care professionals are available at all times of the day and night
  - The importance of immediate support for the relatives increases the sense of security of patients and relatives in hospice care (A)

The working group

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Nurses roles in palliative care

- Different levels can be found in nurses roles as also in palliative care

- Be the skilled and emphatic carer of the patients and families
- Be an expert in palliative care
- Be a consultant to others
- Be the developer and advocate for palliative care

  -> **To manage with these you need competence, self-efficacy and leadership**

- *Cicely Saunders ” We will do all we can not only to help you die peacefully, but also to live until you die.”*

- **The power of nursing** (ICN, Nurses: a voice to lead nursing the world to health)

''Don't underestimate the power that we have: the power in numbers, in associations, in the trust and the credibility of the extraordinary nature of the work we do. Yes, we've done so much, but there is more that we can do! The power and the potential for what we can do not just for ourselves but for the sake of the health of the planet is limitless! But we have to have organisation and cohesion."

- Thank you all!
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