Research in palliative care: who, how, and when? Core competencies framework

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RESPACC, an Erasmus+ project
Case Study
Palliative Sedation EU Project

Who has to do research?

How to practice research?

When research has place?

Content
Palliative Sedation PROJECT as a Case Study

- 5 years research project
- EU founded
- 8 countries participating
- Articulated in 8 WP
- Aim: impact the practice through empirical research with clinical data
Sedarea Paliativă la sfârșitul vieții

Când se efectuează?
Sedarea paliativă este oferită la sfârșitul vieții, atunci când există o suferință intolerabilă din cauza simptomelor și/sau a eștirestului sever, care nu pot fi ameliorate în alt mod.

Ce este?
Nivelul de consistență al pacientului este redus pentru a urma suferința intolerabilă. Mitozolamul este un exemplu de medicament care este utilizat.

Anticipare și îngrijire ulterioră
În boa avansată, sondarea, la intervale regulare, a preferințelor pacienților în materie de îngrijire și discuția cu rudele referitoare la tratament și sedarea paliativă, este conferită unuia practică. În plus, doresc de o persoana de a fi avizată modificarea suferinței și, prin urmare, îngrijirea ulterioră este importantă.

Programării și Terapie
Sedarea paliativă trebuie să fie proporțională cu ameliorarea suferinței intolerabile, necesară pentru trăirea pacient.
Acordarea poate fi:
- Ușoară / Profundă
- Intermitentă / Continuă

Proporționalitatea
Sedarea paliativă trebuie să fie proporțională cu ameliorarea suferinței intolerabile, necesară pentru trăirea pacient.

Cum este evaluat?
Odată sedată, starea de bine a pacientului este evaluată prin semne care indică confortul pacientului și prin consultarea rudei.

Practică sedării paliative
Această practică medicală nu intenționează să scurteze viața, moartea se produce în mod natural. Sedarea paliativă ameliorează suferința intolerabilă a pacientului la sfârșitul vieții.

Medic
Asistent medical
Psiholog
Consilier spiritual
Asistent social
Echipă multidisciplinară

WHO?

WP1 Systematic Review: researcher plus a research nurse with a clinician

WP2 Observational study: 4 clinical teams in different PC services

WP3: Multi-case study and WP4 Moral case deliberation: experts in qualitative review with clinicians

WP5: Cost analysis and policy recommendation: Daniela Mosoiu!
WHO?

As always, a team!
The palliative care team
Clinicians are central, core in palliative care research
Few (professional) researchers (but some)
Inter-disciplinarity: together we achieve more
Multi-disciplinary: we are different and respect each others
1. To know well the clinical context
2. Method and design
   • Multimethod approach: quantitative, qualitative, empirical research, observational study, surveys, cost-analysis, medical education,…
3. Ethics
   • Sensitive research,
   • Cultural factors
4. Very difficult study management
   • To include and to observe 24-72h of sedation patients
5. Data management & informatics
   • Electronical databases, research docs
6. Communication and relationship
   • To share results
A new PC core research COMPETENCIES framework

- The RESPACC ERASMUS+ funded project identify core research competencies for palliative care clinicians.
- **Competence**: the ability to apply knowledge and skills and abilities to successfully perform an activity at work
- We focus on clinicians & in multidisciplinary palliative care teams
- Considering a team level but also an individual level.

*Competența face diferența!*
A new core PC research COMPETENCIES framework

A literature review of research competency frameworks

Nominal Group Technique (NGT) study in 3 countries clinicians

International professional’s consultation.

NEW PC RESEARCH COMPETENCE FRAMEWORK
1. The clinical context
   - 1.1. Awareness of specific aspects of doing research in palliative care contexts

2. Scientific thinking and research design
   - 2.1. Knowledge of basic research principles/terms
   - 2.2. Ability to accurately formulate and understand a research question
   - 2.3. Knowledge about research methodologies
   - 2.4. Ability to read and undertake a basic literature review
   - 2.5. Uses critical and analytical thinking
3. Ethics and regulatory framework for research
   - 3.1. Incorporates and considers the care, safety and protection of all persons in the conduct of research
   - 3.2. Understands the role and remits of research ethics committees in clinical research

4. Study and site management
   - 4.1. Considers the feasibility of a potential project in own working setting
   - 4.2. Coordinates/Conducts the study based on the research protocol
   - 4.3. Documents all the activities in a research study
5. Data management and informatics
   - 5.1. Basic knowledge and skills of statistics, qualitative analysis and informatics
   - 5.2. Basic knowledge and skills of data management (collection, management, analysis)

6. Communications and relationships
   - 6.1. Ability to effectively communicate the content and relevance of clinical research findings for various audiences
   - 6.2. Possesses interviewing and good communication skills
7. Research leadership

- 7.1. Incorporates and promotes team working skills in the conduct of clinical research
- 7.2. Develops and applies the principles and practices of leadership and mentorship in clinical research
# Domain 1. The Clinical Context

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<tr>
<th>Competence</th>
<th>Awareness of specific aspects of doing research in palliative care contexts</th>
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<tbody>
<tr>
<td>1.1</td>
<td>Understands the principles of palliative care and has the ability to apply them during the research process, according to the specific needs of the population. For example, assessing clinical history in a multidimensional way, using only relevant measures and samples, and providing appropriate safe care and treatment. (1) (2) (3) Demonstrates an understanding of the principles of palliative care and takes them into account to describe the objective and scientific techniques used to design studies. Is aware that palliative care populations might be vulnerable in different ways, especially those who have advanced disease or are experiencing distress.</td>
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**Examples of how this competence is demonstrated**

- Ensures that research aims are relevant to palliative care
- Takes account of the potential vulnerability of patients and families (1)
- Understands the specific barriers affecting recruitment and retention of patients in palliative care studies.
- Understands psychological and physical impact of research in palliative care
- Manages, always according to one’s expertise, medical or psychosocial issues that arise during a study (1)
- Ensures that data collection is suitable for palliative care (short and clinically applicable) (1)
Framework usefulness

- To diagnosis the situation of a clinical team regarding research (Quiz)

- To monitor the progress in research
  - For teams or individuals

- To identify areas of training for the team

- To identify profiles of a needed position

- To design research curricula for post-graduate programs
  - Master, specialization

- Etc.
Whenever possible, but deadlines

In parallel with the clinical tasks,

- Step 1: that it means overload may times
- Step 2: with a dedicated person inside the team (i.e., a research nurse)
- Eventually, with the support and power of research PC teams (professional researchers)

Always

- What is not ethical is not to perform research
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Mulțumesc foarte mult.

THANK YOU VERY MUCH.