Integrating Palliative Care in Intensive Care Units:
Organizational and Ethico-Clinical Challenges

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Outline

- What do we know about the integration of palliative care in intensive care?
- What are the challenges?
- Why InPalIn and InPalIn-B?
- Organizational designs and models
- Ethico-clinical decision-making

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What do we know about the integration of palliative care in intensive care?

3

Definition of integrated palliative care

"bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid"

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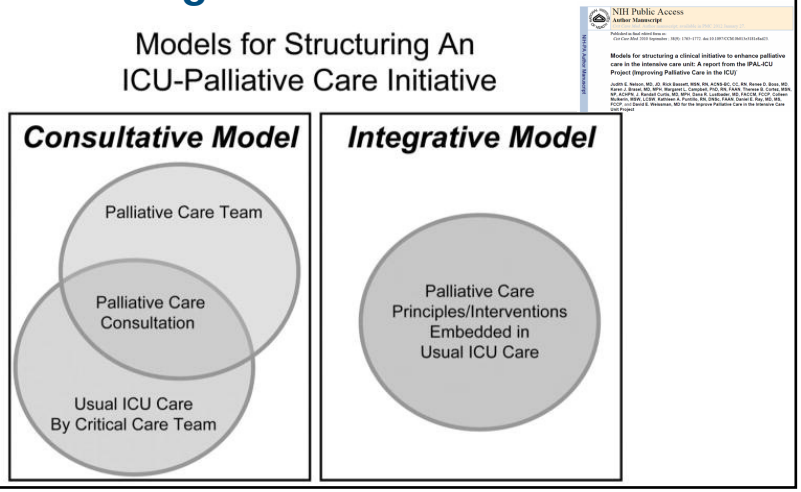
Models for Integrated Palliative Care in ICUs

Models for Structuring An
ICU-Palliative Care Initiative



Models for structuring a clinical initiative to enhance palliative care in the intensive care unit: A report from the IPAL-ICU Project (Improving Palliative Care in the ICU)

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Ethical framework for the integration of PC in ICUs

The integration of palliative care in intensive care can be framed ethically.

By integrating the core principles of palliative care in intensive care, the ethical principles of autonomy, beneficence, non-maleficence and justice are fostered together with the ethical principles of dignity, integrity and vulnerability.

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Integrating palliative care in ICUs:

Several organizational initiatives have been described worldwide

Little is known on the structure, processes, outcomes and ethical framework supporting this integration.

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Why InPalIn and InPalIn-B?

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PLOS ONE

RESEARCH ARTICLE

Compared to Palliative Care, Working in Intensive Care More than Doubles the Chances of Burnout: Results from a Nationwide Comparative Study

Sandra Martins Pereira[1], Carla Margarida Teixeira[1,2,3], Ana Sofia Carvalho[1], Pablo Hernández-Marrero[1]*, InPalIn[1]

Citation: Martins Pereira S, Teixeira CM, Carvalho AS, Hernández-Marrero P, InPalIn (2016) Compared to Palliative Care, Working in Intensive Care More than Doubles the Chances of Burnout: Results from a Nationwide Comparative Study. PLoS ONE 11(9): e0162340. doi:10.1371/journal.pone.0162340

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InPalIn

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Objectives

- To understand the **concepts of integration** and integrated palliative care in intensive care
- To identify the main **barriers and facilitators** of this integration
- To **build and test the implementation of an integration model** of palliative care in intensive care units
- To **ethically frame the integration** and integrated model of palliative care and intensive care

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Methods

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Methods: Purposes of mixing methods

- **Triangulation**
- **Complementarity**
- Development
- Initiation
- Expansion

Is Mixed Methods Social Inquiry a Distinctive Methodology?

Jennifer C. Greene
University of Illinois at Urbana-Champaign

Original Article

PALLIATIVE MEDICINE

Using mixed methods to develop and evaluate complex interventions in palliative care research

Morag C Farquhar
Gail Ewing
Sara Booth

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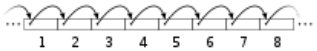
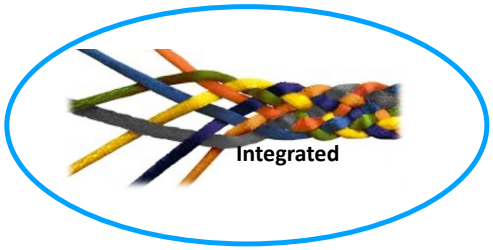
Methods: Potential designs for mixing methods

Sequential





Is Mixed Methods Social Inquiry a Distinctive Methodology?

Jennifer C. Greene
University of Illinois at Urbana-Champaign

Concurrent
(parallel or alongside)

Using mixed methods to develop and evaluate complex interventions in palliative care research

Morag C Farquhar *General Practice and Primary Care Research Unit, Department of Public Health & Primary Care, University of Cambridge, Institute of Public Health, UK*
Gail Ewing *Centre for Family Research, University of Cambridge, UK*
Sara Booth *Addenbrooke's Centre for Clinical Investigation, Addenbrooke's Hospital, Cambridge University Hospitals' NHS Foundation Trust, UK*

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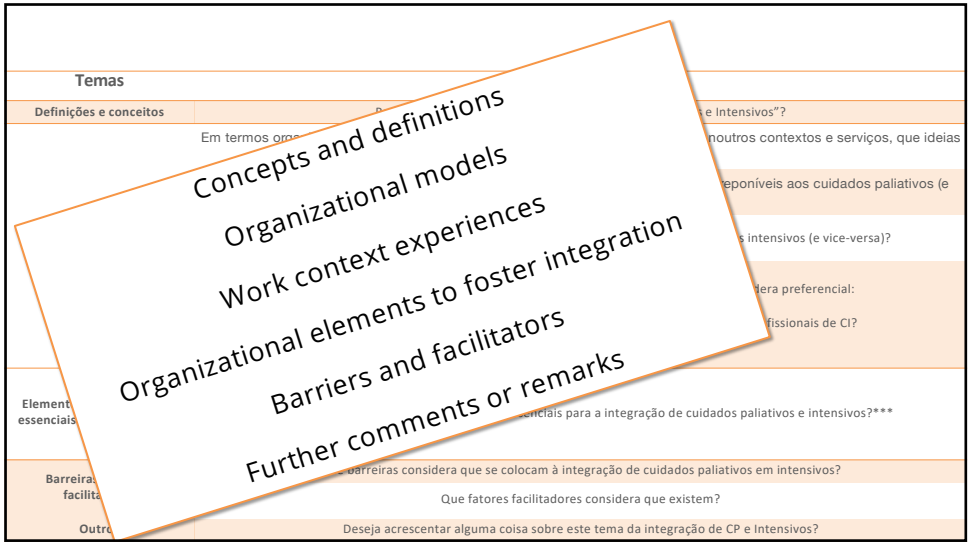

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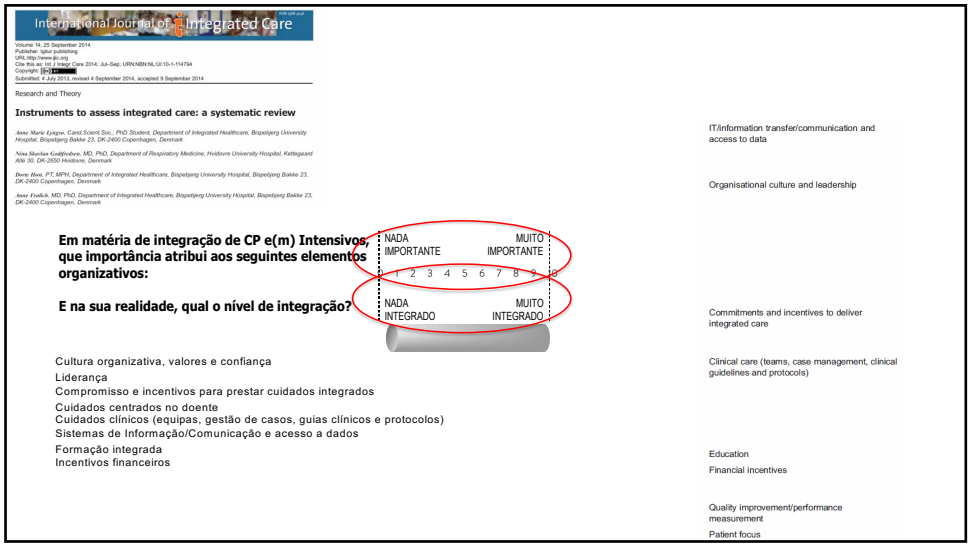
International Journal of Integrated Care
Research and Theory
Instruments to assess integrated care: a systematic review
Em matéria de integração de CP e(m) Intensivos, que importância atribui aos seguintes elementos organizativos:
NADA IMPORTANTE
MUITO IMPORTANTE
0 1 2 3 4 5 6 7 8 9 10
E na sua realidade, qual o nível de integração?
NADA INTEGRADO
MUITO INTEGRADO
Cultura organizativa, valores e confiança
Liderança
Compromisso e incentivos para prestar cuidados integrados
Cuidados centrados no doente
Cuidados clínicos (equipas, gestão de casos, guias clínicos e protocolos)
Sistemas de Informação/Comunicação e acesso a dados
Formação integrada
Incentivos financeiros
IT/information transfer/communication and access to data
Organisational culture and leadership
Commitments and incentives to deliver integrated care
Clinical care (teams, case management, clinical guidelines and protocols)
Education
Financial incentives
Quality improvement/performance measurement
Patient focus

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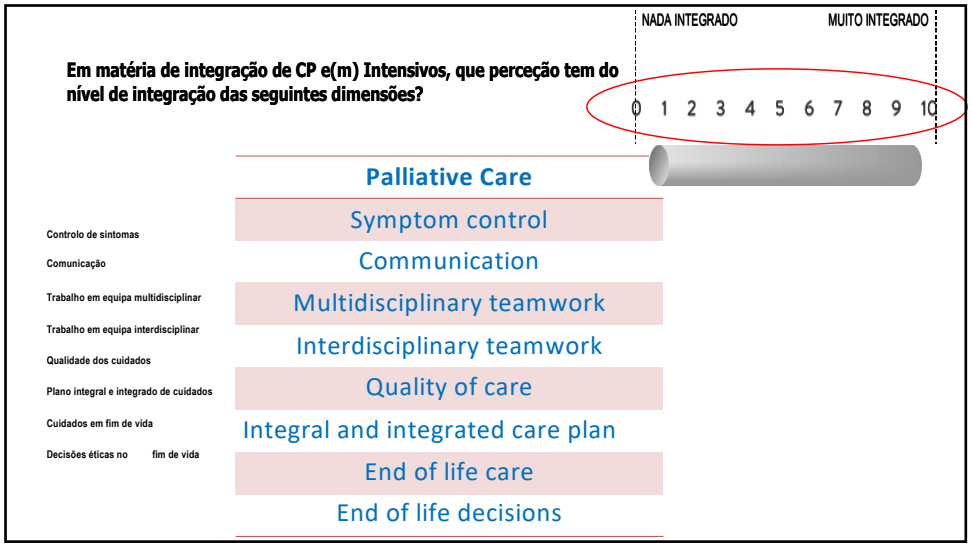
Em matéria de integração de CP e(m) Intensivos, que perceção tem do nível de integração das seguintes dimensões?
NADA INTEGRADO
MUITO INTEGRADO
0 1 2 3 4 5 6 7 8 9 10
Palliative Care
Controlo de sintomas
Symptom control
Comunicação
Communication
Trabalho em equipa multidisciplinar
Multidisciplinary teamwork
Trabalho em equipa interdisciplinar
Interdisciplinary teamwork
Qualidade dos cuidados
Quality of care
Plano integral e integrado de cuidados
Integral and integrated care plan
Cuidados em fim de vida
End of life care
Decisões éticas no fim de vida
End of life decisions

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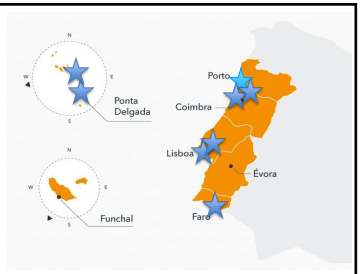
METHODS

Qualitative exploratory and narrative study using in-depth interviews to explore care situations and processes



- **Participants:** Healthcare professionals working in Portuguese palliative and intensive care units.

  38 professionals (16 physicians, 16 nurses, 3 psychologists, 2 social care workers, 1 physiotherapist) across **settings** (20 palliative care and 18 intensive care), **sectors** (public and private) and **cities** (**nationwide**, including the Portuguese **islands**)

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METHODS

- Interviews were conducted by SMP and PHM from June 2016 to October 2018, until reaching theoretical saturation. Verbatim transcripts were performed by SMP and validated by PHM.
- Analysis: An inductive thematic analysis was performed to the transcripts of interviews. SMP and PHM defined the initial themes and codes. Any discrepancies were discussed until reaching consensus.

NVIVO

- Ethics approval was given by the Ethics Research Lab of the Institute of Bioethics, UCP [02/2016] and also by all participant healthcare institutions.
- All participants provided informed consent and data was pseudonymized before the analysis.

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Analysis

Qualitative data	Quantitative data
• Thematic content analysis	• Descriptive analysis • Comparative analysis (PC vs IC)

NVIVO

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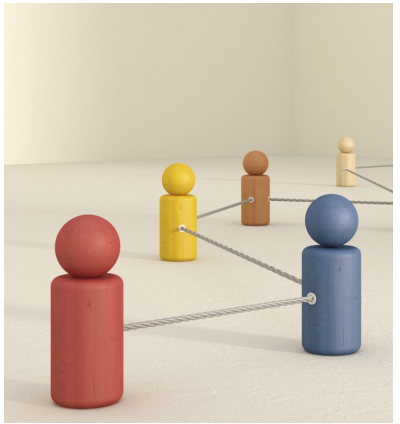
Organizational designs and models



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Results

Professionals had **different concepts of integration**.

While intensivists considered the integration as a way of **improving end-of-life care** in intensive care units, palliative care professionals defined it as a way of **promoting patient-centred care**.

"The integration of palliative care in our unit could help us improve the care that we give to our patients at the end of life" (#12, IC Nurse)

"In my perspective, the integration of palliative care in intensive care is a way of fostering patient-centred care and helping our colleagues from the intensive care unit to see the person and not the patient or the organ or system failures" (#3, PC physician)

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Results

Organizational models: Palliative care professionals defended a consultation model, introducing the role of a specialized palliative care team in liaison with the intensive care team. Intensive care professionals preferred an education model, fostering their own competencies in palliative care.

"A mixed model would be the ideal! We could combine our action as consultative team in palliative care with providing additional education about palliative care to our colleagues from the intensive care unit" (#10, PC Nurse)

"I think that it would be enough if we (professionals working in intensive care) would receive complimentary training in palliative care. Actually, we provide palliative care already… each time we make the decision to forgo some type of life-sustaining treatment we provide palliative and comfort care. Therefore, my choice would be an educational model" (#18, IC physician)

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Results

The **organizational dimensions most valued** by both palliative care and intensive care professionals were:

Patient-centred care (93% of respondents measured this dimension as being “very important”)

Education (86% measured as “very important”)

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Barriers and Facilitators

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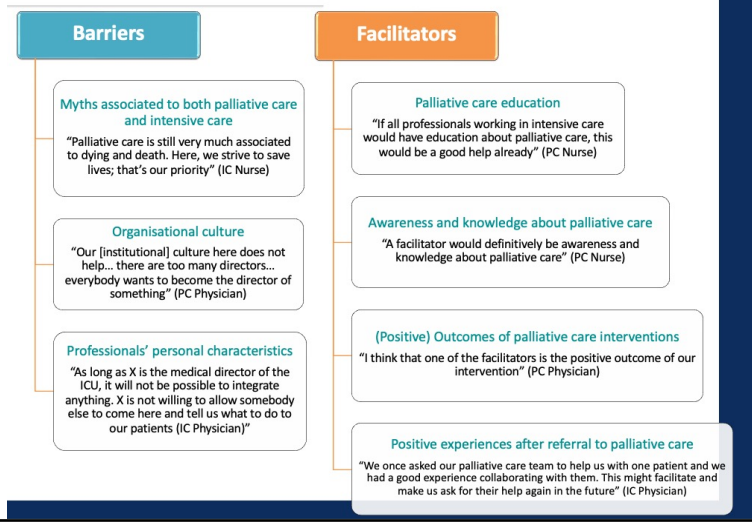
Results



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Ethico-clinical challenges

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Results: A Spectrum of ethical issues

Theme	Categories	Quotations
Concept of integration	Integration as a way of improving end-of-life care	"Integrating palliative care can help us to improve end-of-life care for patients in our [IC] unit." (Interview#12 IC Nurse)
Need for early integration	Prevention of invasive treatments	"Maybe, if we integrate PC earlier, we can prevent some patients from burdensome, futile treatments" (Interview#14 IC Physician)
Organizational models of integration	Mixed-model preferred by palliative care professionals	"I think that a mixed-model, combining both PC consulting by a specialized PC support team and education about PC for professionals working in IC would be the best way of promoting this integration" (Interview#10 PC Nurse)
	Educational model preferred by intensive care professionals	"It would be good enough if we would be trained about PC. We already provide PC when we withdraw life-sustaining measures… so, education on PC would be the best model, I think" (Interview#18 IC Physician)
Integration from a bioethical perspective	Promoting patient autonomy	"By integrating PC in IC, maybe we could help some patients to die in the place of their preference, with their loved ones… without being surrounded by all those machines and technical stuff that they have in the IC unit" (Interview#1 PC Nurse)
	Protecting and caring for vulnerable patients	"Our patients here [IC] are highly vulnerable… maybe by integrating PC in our practices, we can protect and care for them better than we do now… allowing their loved-ones to be with them… protecting them from any harm…" (Interview#7 IC Physician)

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Results: A Spectrum of ethical issues

Theme	Categories	Examples of quotations
Integration from a bioethical perspective	Promoting patient **autonomy**	*"By integrating PC in IC, maybe we could help some patients to die in the place of their preference, with their loved ones… without being surrounded by all those machines and technical stuff that they have in the IC unit"* (Interview#1 PC Nurse)
	Protecting and caring for **vulnerability**	*"Our patients here [IC] are highly vulnerable… maybe by integrating PC in our practices, we can protect and care for them better than we do now… allowing their loved-ones to be with them… protecting them from any harm…"* (Interview#7 IC Physician)

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InPalIn-B

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BACKGROUND

- Burns are a global public health problem, accounting for around 300,000 deaths annually.
- 25% of patients aged 45-65 with severe burns die.
- Burns cause unbearable suffering and have significant consequences for patients, families, healthcare teams and systems.

(Bayuo et al., 2019; Mock C 2008; Ray et al., 2017; WHO 2018; WHO, 2019)

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Background

- Burns are a **serious illness with traumatic injuries that may represent a personal catastrophe** because of the physical, psychological, social and economic consequences for patients and their families.

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Background

- **End-of-life care** is a major step in the care provided to critically burned patients and their families.
- It requires a specific set of **competencies** to enable improved quality of life, comfort, optimum symptom management, and family support.

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Background

- Nonetheless, **end-of-life care is often neglected, particularly in burn intensive care units**
- **Dying, death and end-of-life care** are rarely studied and often perceived as a clinical **failure**.

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BACKGROUND


Review Article

Do patients, families, and healthcare teams benefit from the integration of palliative care in burn intensive care units? Results from a systematic review with narrative synthesis

André Filipe Ribeiro[1], Sandra Martins Pereira[2,3,4], Barbara Gomes[5,6] and Rui Nunes[5,7]

- Evidence suggests that the integration of palliative care in burn intensive care units improves patients' comfort and care, end-of-life care, decision-making processes, and family care.
- Multidisciplinary teams may experience lower levels of burden as result of integrating palliative care in burn intensive care units.
- However, very little is known on how to foster this integration and its outcomes.

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Delivery of end-of-life care models: process and structure

The term **'model' of end-of-life care provision** refers to any **process or structured care model** involving multiple components including "**who delivers** (e.g., professionals) the intervention (specialist or generalist palliative or end-of-life care), **where** (setting: burn intensive care units), **to whom** (critically burned patients), **when** (i.e., timing and duration), **how** (e.g., face to face) and **for what purpose** (i.e., expected outcomes)"

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OBJECTIVES

- To identify triggers for palliative care referral in critically burned patients.
- To explore the organizational models of end-of-life care provision in burn intensive care units during the COVID-19 pandemic
- To identify the ethical challenges in burn intensive care units, particularly during the COVID-19 pandemic

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Sampling and recruitment

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Sample and recruitment

Purposive sampling
5 National Burn Centres
(Burn Intensive Care Units):

- Centro Hospitalar de São João, EPE
- Centro Hospitalar Universitário de Coimbra, EPE
- Centro Hospitalar Lisboa Norte, EPE
- Centro Hospitalar de Lisboa Central, EPE
- Hospital da Prelada

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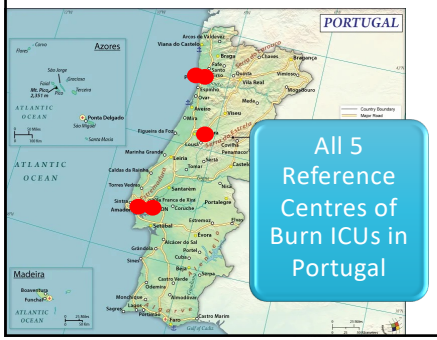
METHODS



All 5 Reference Centres of Burn ICUs in Portugal

3 Burn ICUs participated

15 Professionals interviewed
- 12 Nurses
- 3 Physicians

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Methods

Semi-structured interviews

7 Dimensions

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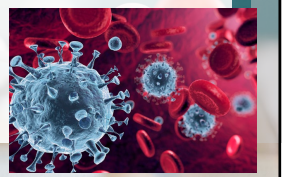
Data collection

- Interviews were conducted by 1 interviewer under the supervision and with the participation of other 2 experienced interviewers
- Interviews conducted and recorded via Videoconference
- July – October 2020
- 45 to 90 minutes



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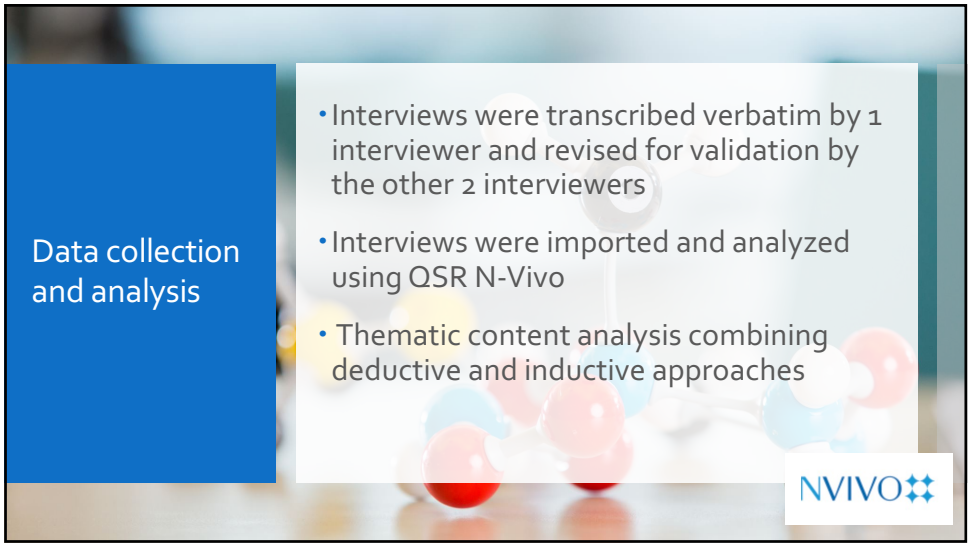
Data collection and analysis
• Interviews were transcribed verbatim by 1 interviewer and revised for validation by the other 2 interviewers
• Interviews were imported and analyzed using QSR N-Vivo
• Thematic content analysis combining deductive and inductive approaches
NVIVO

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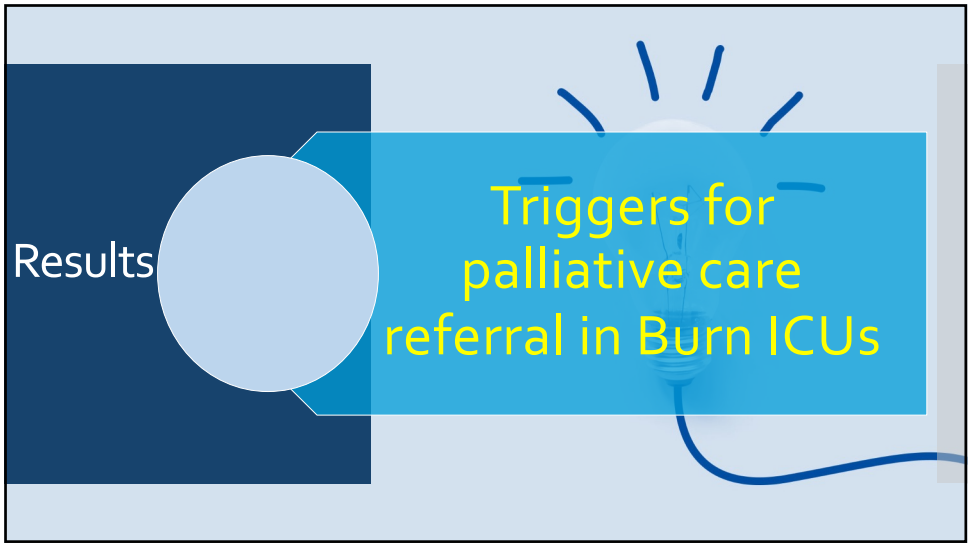
Results
Triggers for palliative care referral in Burn ICUs

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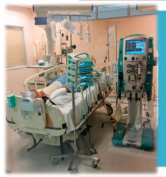
Results

Three main Triggers

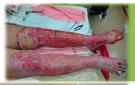
Burn severity and extension
- 3rd Degree Burns
- +80% Body Surface Burned



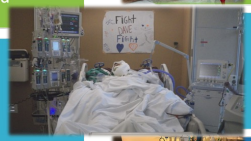
Co-morbidities
- Cancer
- Organ Failure
- Metabolic failure
- Dementia
- Old age +80

Multiorgan failure

Four additional Triggers



Rehabilitative palliative care related to patients' suffering and changes in body image



Family suffering and/or dysfunctional and complex family processes

Long stay in the burn intensive care unit

Uncontrolled pain

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Results

Ethical challenges and decisions

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Ethical challenges and decisions	Quotes
Intensifying pain and symptom control	*"When we know that the patient is dying and we reach a consensualized decision to stop with curative treatments, we usually intensify pain and symptom control, and even sedate a patient so he can die without suffering"* (I5)
Therapeutic obstinacy	*"The other day… we had an 80-years old patient… the two legs amputated already and in sepsis… are we going to insist with aggressive treatment measures to prolong his life? Is this the right way to go?"* (I3) *"We go till the end… till there is nothing else we can do to escalate treatment options"* (I7)
Advance directives	*"Now, we can access the patient's living will and we can get a better understanding about his/her wishes prior to getting critically burned"* (I4)

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Ethical challenges and decisions	Quotes
Managing hope and expectations	*"We give our best to communicate with the patient's family and try to manage their hope and expectations realistically. We are here for them. Even if they are not allowed to come into the unit, I go out there to the visit corridor and speak with them"* (I2)
Family involvement in the decision-making process	*"We always involve the family in the decision-making process"* (I2)

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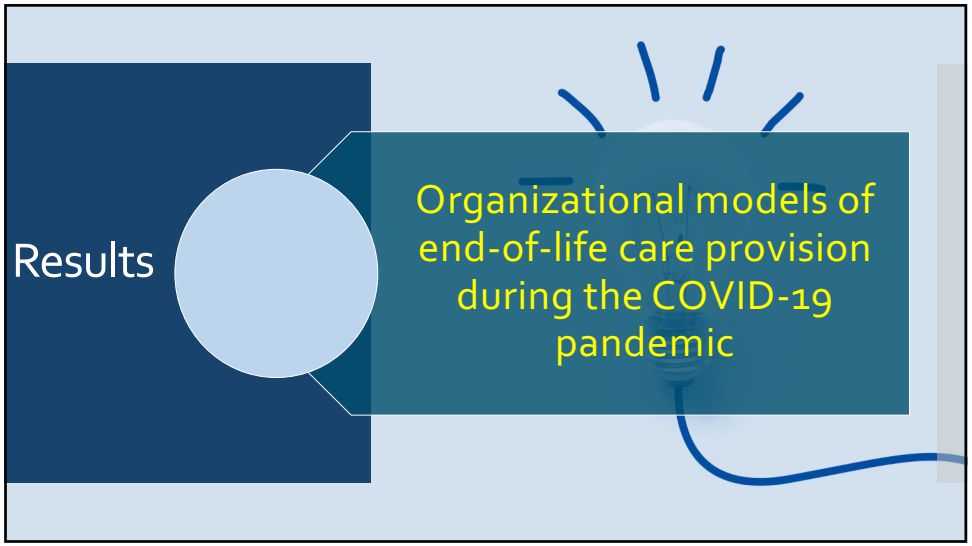

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Organizational models of end-of-life care provision during the COVID-19 pandemic		
Theme	**Sub-theme**	**Quotes**
Risk of infection/sepsis and visiting procedures	Flexibility and by-passing visiting restrictions	*"Because of the pandemic, visits were banned in the whole hospital. However, when we know that a patient is dying, one relative is allowed to come in and say goodbye to his/her loved one through the visiting corridor and inter-communicator or even coming inside fully equipped with PPE."* (I2)
	Struggle with visiting restrictions	*"We had one case. It was truly heartbreaking… we wanted to allow the family to come, and be with the patient who was dying, but they were so afraid of the pandemic that they decided not to. It was really difficult for us to see this"* (I1)
	Videoconferencing	*"Now, visits are not allowed. Our strategy is to use our personal mobiles and make videocalls between the patient and his/her loved one, whenever this is still possible"* (I2) *"Visits were banned. We have been trying to speak with our director to be more flexible about this, especially when a patient is dying, but it isn't easy… so, we use our personal phones to call the family and keep them informed"* (I4)

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Organizational models of end-of-life care provision during the COVID-19 pandemic		
Theme	**Sub-theme**	**Quotes**
Hampered consultation model	Specialist advice from other professionals is hampered during the pandemic	*"We used to be able to consult the psychiatrist for emotional support. Now, with the pandemic, this is restricted and neither patients nor families can have this support"* (I6)
Difficulties in case management	Physicians on call	*"We have a permanent physician (plastic surgeon) here at the unit. However, the anesthetists are not always the same; they are on call every four to seven days. Therefore, the collaborative process of care does not always continuity and fast decision-making. With the pandemic, this has worsened."* (I12)
Decisions on how Burn ICUs are reorganized	*"Under normal circumstances, because of the severity of burn injuries, family members sometimes even doubt whether it was really their loved one who died. With the visiting restrictions, this has become a dramatic and devastating trauma" (I11)*	

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Discussion

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Thank you
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