Ethical challenges in palliative and end-of-life care:

Decision-making processes under uncertainty, risk, and asymmetry of information

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CONFLICT OF INTEREST DISCLOSURE

I have no potential conflict of interest to report

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Outline

- Ethico-clinical challenges in palliative and end-of-life care
- Ethical decision-making frameworks
- Decision-making under uncertainty, risk and asymmetry of information: DELiCare
- Enhancing ethico-clinical decision-making in palliative care

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Ethico-clinical challenges in palliative and end-of-life care

4

Facts

- In palliative and end-of-life care, symptom control poses challenges
- Some of these challenges are ethico-clinical
- What does "ethical challenges" mean?

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What does "ethical challenges" mean?

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Challenge

The situation of being faced with something that needs great mental or physical effort in order to be done successfully and therefore tests a person's ability

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BMC Medical Ethics

RESEARCH Open Access

Defining ethical challenge(s) in healthcare research: a rapid review

Guy Schofield[1,2*], Mariana Dittborn[3], Lucy Ellen Selman[4] and Richard Huxtable[5]

Ethical challenges

- Ethical issues
- Ethical concerns
- Ethical dilemmas
- Ethical aspects
- Ethical conflicts
- Ethical considerations
- Ethical tensions
- Ethical problems
- Ethical uncertainties
- Moral dilemmas
- Moral problems

Table 4 Use of terms closely related to 'ethical challenge'

Number of studies containing the term (total = 75)	Term
> 30	Ethical issues
20–30	Ethical concerns Ethical dilemmas
	Ethical aspects Ethical conflicts Ethical considerations Ethical problems
	Ethically challenging/ demanding/difficult situations Ethical difficulties Moral challenges
	Ethical dimensions Ethical questions Ethical tensions Moral dilemmas
	Ethical complications Ethical components Ethical difficulties Ethical discussions Ethical disquiet Ethical elements Ethical factors Ethical obstacles Ethical struggles Ethical uncertainties Moral conflict Moral courage Moral considerations Moral issues Moral problems Moral question Morally relevant topics Moral situations

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BMC Medical Ethics
RESEARCH
Open Access
Defining ethical challenge(s) in healthcare research: a rapid review
Ethical Challenges
Four approaches:
1) definition through concepts;
2) reference to moral conflict, moral uncertainty or difficult choices;
3) definition by study participants; or
4) challenges as linked to their ability to generate emotional or moral distress within healthcare professionals.

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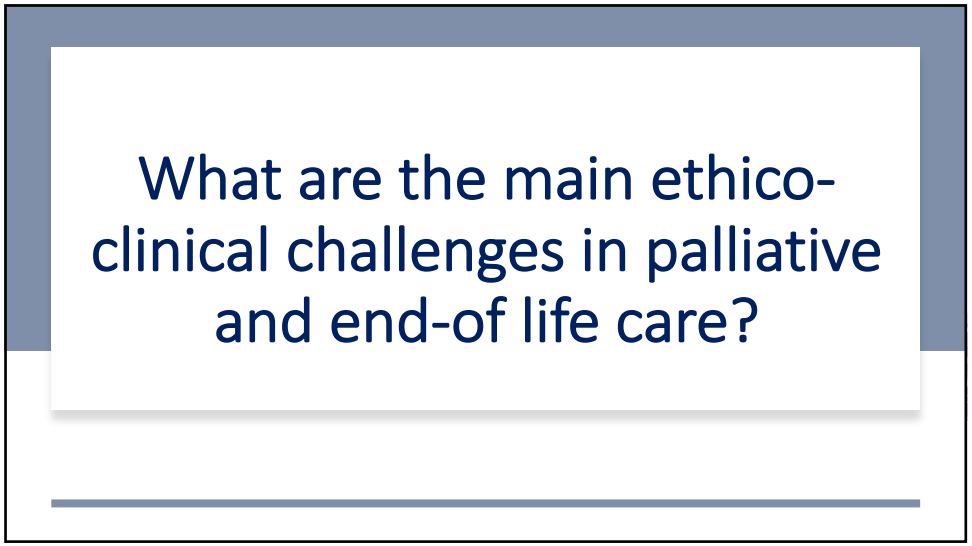
What are the main ethico-clinical challenges in palliative and end-of life care?

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Ethico-clinical challenges in palliative and end-of-life care (1/3)

- Prognostication
- Disclosing the diagnosis or prognosis
- Justice in the access to palliative care
- Advance Care Planning
- Advance Directives
- 'Do Not Attempt Cardio-Pulmonary Resuscitation' (DNACPR) Decisions
- Treatment escalation decisions
- Palliative sedation (for distress in the terminal phase)

(Allan, 2015; Cerny, 2020; Farris et al; 2021; Ferraz Gonçalves, 2009; Kendall, 2000; Sulmasy, 2007; Allard & Fortin, 2017; Crowther & Costello, 2017; McClung, 2017; Barbosa, 2016; Monterosso et al., 2016; Hernández-Marrero et al. 2015; Shaw & Battin, 2015; Schildman et al., 2015; Nicholas et al., 2014; Rosenberg & Speice, 2013; Pavlish et al., 2011; Martins Pereira, 2010)

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Ethico-clinical challenges in palliative and end-of-life care (2/3)

- Organ donation after withdrawal of life-sustaining treatments
- "Therapeutic obstinacy" (needless or disproportionate treatment)
- Forgoing treatments decisions (non-treatment decisions): Withholding/withdrawing
- Treatment refusal
- Double effect
- Research with vulnerable groups

1. The action itself is good or at least neutral;
2. The good effect, not the bad effect, is what is intended;
3. The good effect is not produced by the bad effect;
4. There is a proportionately grave reason for permitting the bad effect.

(Allan, 2015; Cerny, 2020; Farris et al; 2021; Ferraz Gonçalves, 2009; Kendall, 2000; Sulmasy, 2007; Allard & Fortin, 2017; Crowther & Costello, 2017; McClung, 2017; Barbosa, 2016; Monterosso et al., 2016; Hernández-Marrero et al. 2015; Shaw & Battin, 2015; Schildman et al., 2015; Nicholas et al., 2014; Rosenberg & Speice, 2013; Pavlish et al., 2011; Martins Pereira, 2010)

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Ethico-clinical challenges in palliative and end-of-life care (3/3)

(Keeping) Promises

Work related problems (e.g., moral distress, burnout, compassion fatigue, PTSD) and professionals' increased vulnerability

Integration, transition and continuity of care (privacy and confidentiality)

Wish to hasten death / Desire to die

Euthanasia and (Physician) Assisted Suicide

(Allan, 2015; Cerny, 2020; Farris et al; 2021; Ferraz Gonçalves, 2009; Kendall, 2000; Sulmasy, 2007; Allard & Fortin, 2017; Crowther & Costello, 2017; McClung, 2017; Barbosa, 2016; Monterosso et al., 2016; Hernández-Marrero et al. 2015; Shaw & Battin, 2015; Schildman et al., 2015; Nicholas et al., 2014; Rosenberg & Speice, 2013; Pavlish et al., 2011; Martins Pereira, 2010)

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JOURNAL OF PALLIATIVE MEDICINE
Volume 20, Number 1, 2017
Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2016.0350

Position Statement

International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide

Liliana De Lima, MHA,[1] Roger Woodruff, MD,[2] Katherine Pettus, PhD,[1] Julia Downing, RN, PhD,[3] Rosa Bultrago, MCPH,[4] Esther Muryoro, MD,[5] Chitra Venkateswaran, MD,[6] Sushma Bhatnagar, MD,[7] and Lukas Radbruch, MD[8]

Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104–116
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https://doi.org/10.1177/0269216315616524

SAGE journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch[1,2], Carlo Leget[3], Patrick Bahr[1], Christof Müller-Busch[4,5], John Ellershaw[6], Franco de Conno[7], Paul Vanden Berghe[8], and on behalf of the board members of the EAPC

TABLE 1. DEFINITION OF TERMS (ADAPTED FROM THE EAPC)[12]

Euthanasia	A physician (or other person) intentionally ending the life of a person by the administration of drugs, at that person's voluntary and competent request.
Assisted suicide	A person intentionally helping another person to terminate his or her life, at that person's voluntary and competent request.
Physician-assisted suicide	A physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request.
Nontreatment decisions	Withholding or withdrawing medical treatment from a person either because of medical futility or at that person's voluntary and competent request.
Palliative sedation	The monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers.

EAPC, European Association for Palliative Care.

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Ethical decision-making frameworks

Ethical challenges in palliative and end-of-life care

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A Framework for Ethical Decision-Making: Version 6.0
Ethics Shareware (Jan. '01)

by Michael McDonald[1]
With additions by Paddy Rodney and Rosalie Starzomski[2]

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1. Collect information and identify the problem

1. Be alert; be sensitive to morally charged situations
   - *Look behind the technical requirements.*
   - *Use ethical resources and moral intuition.*
2. Identify what you know and don't know
   - *Gather information from the patient, family, other healthcare providers.*
   - *Decisions may have to be made before a full story is known…*
3. State the case briefly with as many of the relevant facts and circumstances as you can gather within the decision time available
   - *What decisions have to me made? Who are the decision-makers?*
   - *Be alert to (potential) CoI*
4. Consider the context of decision-making
   - *Clinical issues + Patient preferences + Quality of life / death + Contextual features*

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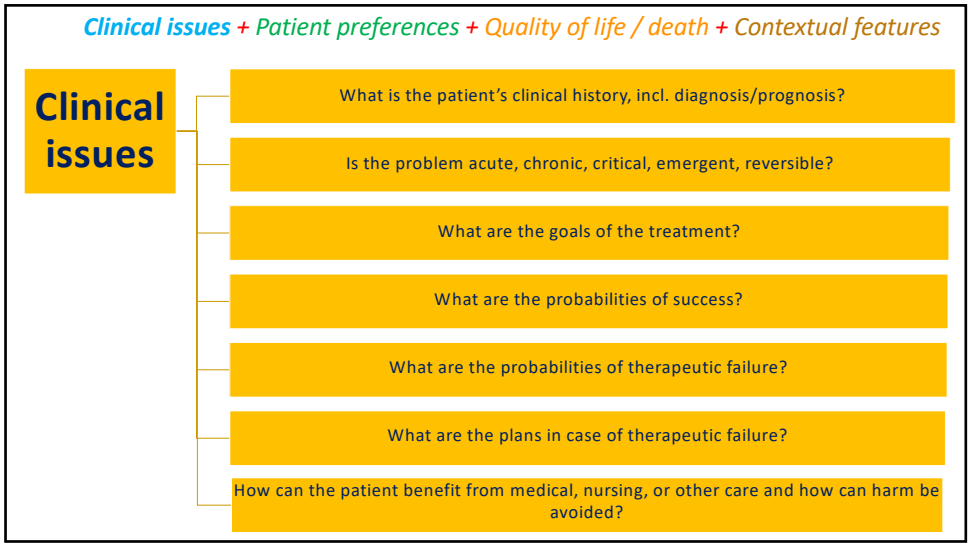
Clinical issues + Patient preferences + Quality of life / death + Contextual features
Clinical issues
What is the patient's clinical history, incl. diagnosis/prognosis?
Is the problem acute, chronic, critical, emergent, reversible?
What are the goals of the treatment?
What are the probabilities of success?
What are the probabilities of therapeutic failure?
What are the plans in case of therapeutic failure?
How can the patient benefit from medical, nursing, or other care and how can harm be avoided?

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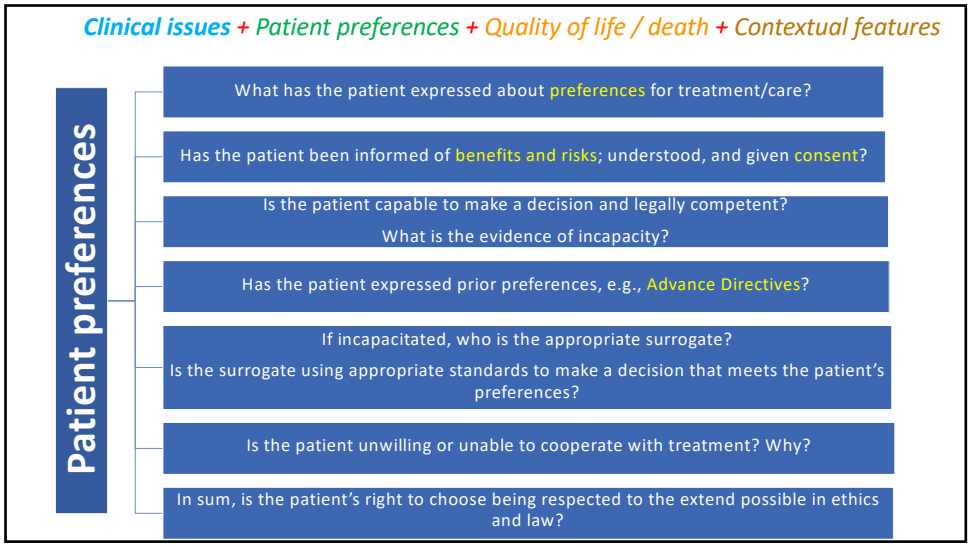
Clinical issues + Patient preferences + Quality of life / death + Contextual features
Patient preferences
What has the patient expressed about preferences for treatment/care?
Has the patient been informed of benefits and risks; understood, and given consent?
Is the patient capable to make a decision and legally competent?
What is the evidence of incapacity?
Has the patient expressed prior preferences, e.g., Advance Directives?
If incapacitated, who is the appropriate surrogate?
Is the surrogate using appropriate standards to make a decision that meets the patient's preferences?
Is the patient unwilling or unable to cooperate with treatment? Why?
In sum, is the patient's right to choose being respected to the extend possible in ethics and law?

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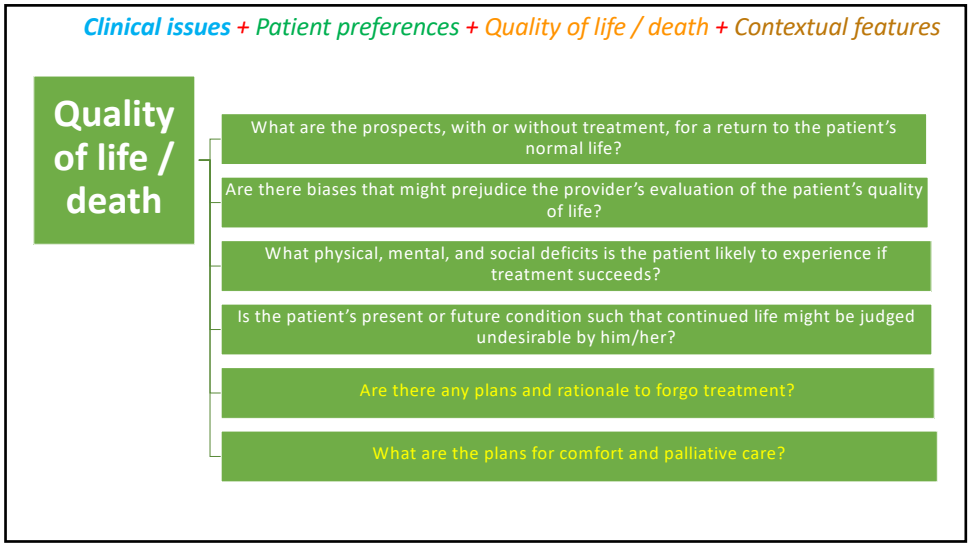
Clinical issues + Patient preferences + Quality of life / death + Contextual features
Quality of life / death
What are the prospects, with or without treatment, for a return to the patient's normal life?
Are there biases that might prejudice the provider's evaluation of the patient's quality of life?
What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?
Is the patient's present or future condition such that continued life might be judged undesirable by him/her?
Are there any plans and rationale to forgo treatment?
What are the plans for comfort and palliative care?

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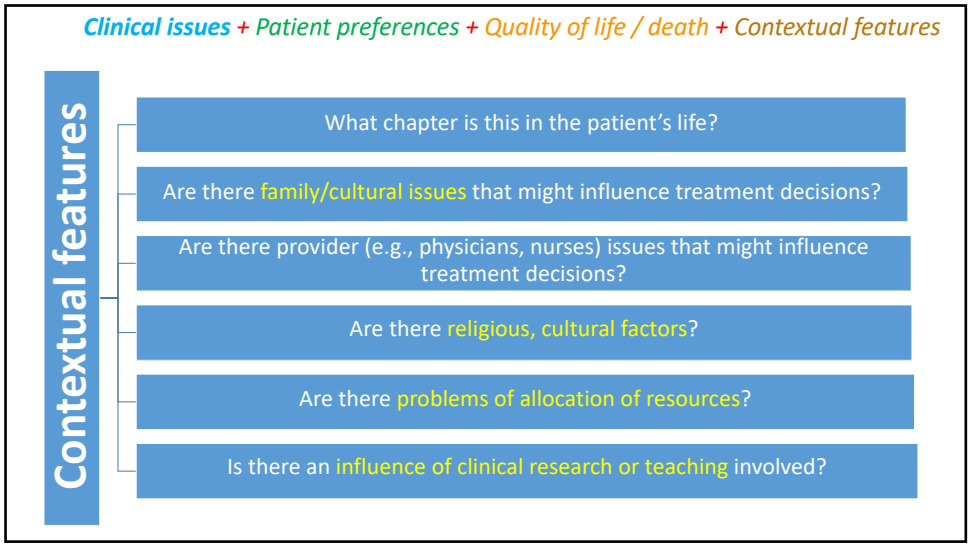
Clinical issues + Patient preferences + Quality of life / death + Contextual features
Contextual features
What chapter is this in the patient's life?
Are there family/cultural issues that might influence treatment decisions?
Are there provider (e.g., physicians, nurses) issues that might influence treatment decisions?
Are there religious, cultural factors?
Are there problems of allocation of resources?
Is there an influence of clinical research or teaching involved?

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A Framework for Ethical Decision-Making: Version 6.0
Ethics Shareware (Jan. '01)

by Michael McDonald[1]
With additions by Paddy Rodney and Rosalie Starzomski[2]

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2. Specify feasible alternatives

Stake the live options at each stage of decision-making and ask what likely consequences are of various decisions.

Always take into account good or bad consequences for all affected persons.

Be honest! Encourage others to be honest.

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3. Use your ethical resources to identify morally significant factors in each alternative

1. **Principles:** Autonomy, Non-maleficence, Beneficence, Justice, Fidelity, Vulnerability, Integrity, Dignity
   Have promises been made? Will this harm somebody? Are we treating other fairly? Are we being faithful to professional and institutional roles? Are we living up to the trust relationships that we have with others?
2. **Moral models**
3. **Use ethically informed sources**
   Policies, source materials, professional norms and codes of conduct
4. **Context**
5. **Personal judgements**
   Yours, Your associates' ones, Your trusted friends or advisors'
6. **Organized procedures for ethical consultation**
   Formal case conference(s), ethics committee, ethics consultant

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4. Propose and test possible resolutions

A Framework for Ethical Decision-Making: Version 6.0
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1. Find the best consequences overall
   Propose a resolution! Select the best alternative!

2. Perform a sensitivity analysis
   What would alter your decision? Be critical!

3. Consider the impact on ethical performance of others
   Are you setting a good example?
   Would a good person do this?
   What if everyone in these circumstances did this?
   Will this remain trust relationship with others?
   Does it still seem right?

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5. Make your choice

Live with it!

Learn from it!

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Making an Ethical Decision

Recognize an Ethical Issue

1. Could this decision or situation be damaging to someone or to some group? Does this decision involve a choice between a good and bad alternative, or perhaps between two "goods" or between two "bads"?

2. Is this issue about more than what is legal or what is most efficient? If so, how?

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Get the Facts

3. What are the relevant facts of the case? What facts are not known? Can I learn more about the situation? Do I know enough to make a decision?

4. What individuals and groups have an important stake in the outcome? Are some concerns more important? Why?

5. What are the options for acting? Have all the relevant persons and groups been consulted? Have I identified creative options?

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Evaluate Alternative Actions

6. Evaluate the options by asking the following questions:

- Which option will produce the most good and do the least harm? (The Utilitarian Approach)
- Which option best respects the rights of all who have a stake? (The Rights Approach)
- Which option treats people equally or proportionately? (The Justice Approach)

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Evaluate Alternative Actions

6. Evaluate the options by asking the following questions:

- Which option best serves the community as a whole, not just some members? (The Common Good Approach)
- Which option leads me to act as the sort of person I want to be? (The Virtue Approach)

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Make a Decision and Test It

7. Considering all these approaches, which option best addresses the situation?

8. If I told someone I respect—or told a television audience—which option I have chosen, what would they say?

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Act and Reflect on the Outcome

9. How can my decision be implemented with the greatest care and attention to the concerns of all stakeholders?

10. How did my decision turn out and what have I learned from this specific situation?

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A Model for Ethical Problem-Solving
The Five-Step Model

Journal of Psychosocial Oncology

ISSN: 0734-7332 (Print) 1540-7586 (Online) Journal homepage: http://www.tandfonline.com/loi/wjpo20

The Anatomy and Physiology of Ethical Decision Making in Oncology

Amy Marie Haddad PhD, RNC

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To link to this article: http://dx.doi.org/10.1300/J077V11N01_05

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A Model for Ethical Problem-Solving
The Five-Step Model

1. Respond to the "sense" or feeling that something is wrong
2. Gather information / assessment
3. Identify the ethical problem / moral diagnosis
4. Seek a resolution
5. Work with other to determine a course of action

(Haddad, 1993)

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A Model for Ethical Problem-Solving

The Five-Step Model allows to:

Apply	Delineate	Distinguish	Define	Analyze
Apply a stepwise process to systematically solve an ethical problem in a clinical case	Delineate the steps in a five-step model for ethical decision-making	Distinguish between clinical, situational and legal information necessary for sound ethical decisions	Define ethical principles commonly encountered in practice, such as respect for autonomy, beneficence, non-maleficence, and veracity, among other ethical principles	Analyze courses of action to determine which are ethically more adequate

(Haddad, 1993)

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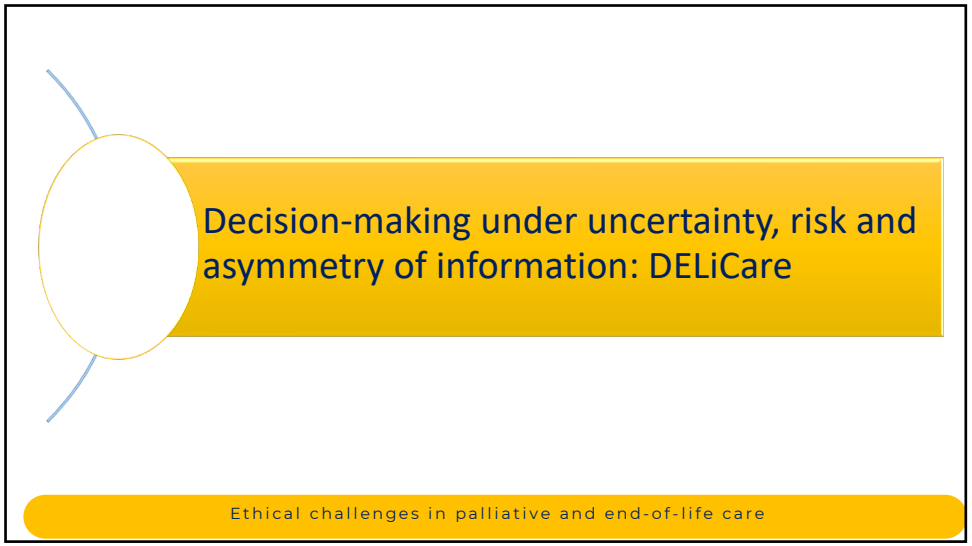

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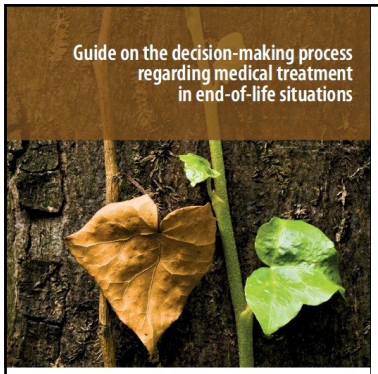

Project DELiCare – Decisions, Decision-making, and End-of-Life Care: Ethical Framework and Reasoning

- DELiCare is an innovative project aiming to provide a culturally sensitive, rational framework on palliative care and end-of-life decisions in Portugal and Spain.
- It also aims to contribute to the implementation and international discussion of the Guide of the Council of Europe on the decision-making process regarding medical treatment in end-of-life situations.

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Project DELiCare – Decisions, Decision-making, and End-of-Life Care: Ethical Framework and Reasoning

i. To develop an international ethical discussion of the Guide of the Council of Europe (CoE) and other international ethical decision-making frameworks considering their potential to improve end-of-life care and decision-making
ii. To analyze how stakeholders involved in PC and end-of-life decision-making value the recommendations of these guidelines and frameworks;
iii. To describe end-of-life care and end-of-life decisions in Portugal and Spain

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DELiCare

Three intertwined studies are designed as follows.

- International and ethical discussion of the CoE Guide and other international frameworks

Study 1

Study 2

- Description of stakeholders' perspectives on the dimensions of the CoE Guide and other frameworks

- Description of end-of-life decisions and end-of-life care provision in Portugal and Spain

Study 3

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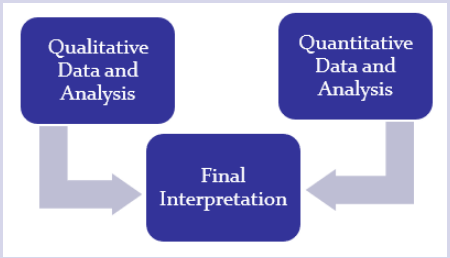
DELiCare



Concurrent mixed-methods triangulation design

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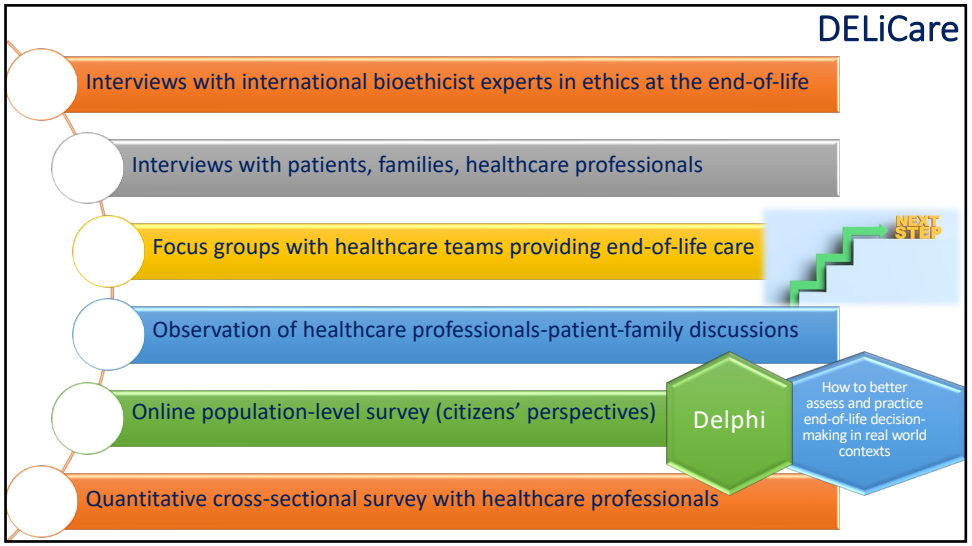
DELiCare
Interviews with international bioethicist experts in ethics at the end-of-life
Interviews with patients, families, healthcare professionals
Focus groups with healthcare teams providing end-of-life care
NEXT STEP
Observation of healthcare professionals-patient-family discussions
Online population-level survey (citizens' perspectives)
Delphi
How to better assess and practice end-of-life decision-making in real world contexts
Quantitative cross-sectional survey with healthcare professionals

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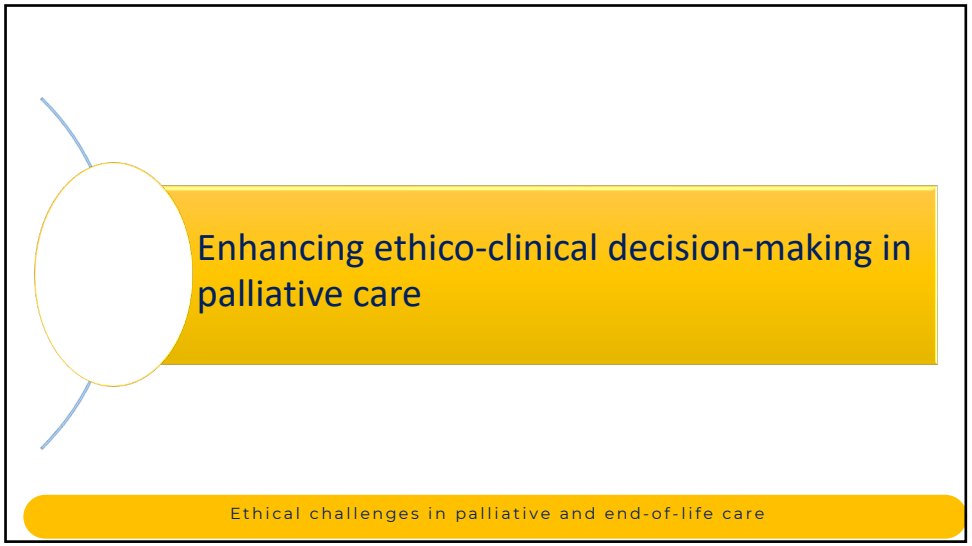
Enhancing ethico-clinical decision-making in palliative care
Ethical challenges in palliative and end-of-life care

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Professionals' Ethical Sensitivity

- Human suffering, vulnerability, frailty, end of life, dying and death
- Complex ethical and clinical decisions
- Interdisciplinary palliative care teams
- Team cultures differ (e.g., identities, values)
- Decision-making: Groupthink, polarization
- Team conflicts

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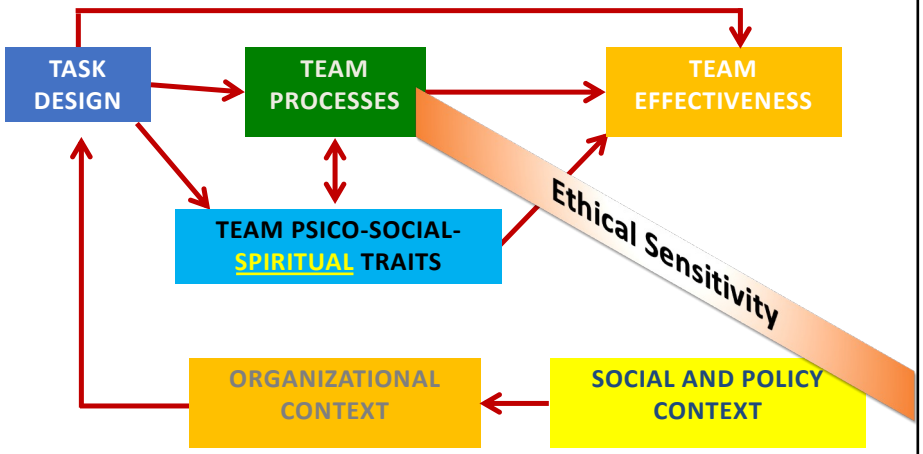
INTEGRATED (HEALTHCARE) TEAM EFFECTIVENESS MODEL



(Adapted by Hernández-Marrero, 2016, from Cohen & Bailey, 1997; Fired et al. 1988; and Shwiekhart & Smith-Daniels, 1996)

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High Quality Teams & Effectiveness in Ethico-Clinical Decision-Making

- Communication and commitment
- Coordination
- Balance of member contributions
- Mutual support, effort and cohesion
- Trusting relationships
- Shared philosophies
- Clear roles
- Respect for unique role contributions
- Shared decision-making

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Psychological Empowerment

"A personal sense of control in the workplace as manifested in four beliefs about the person-work relationships:

meaning,
competence,
self-determination and
impact"

(Spreitzer, 1995; Quinn & Spreitzer, 1997)

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Psychological Empowerment

Meaning reflects as sense of purpose or personal connection about work.

"The work I do is extremely meaningful to me"

"Through my work, my life gets a different meaning"

(Spreitzer , 1995; Hernández-Marrero, 2006; Martins Pereira, 2011)

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Psychological Empowerment

Competence indicates that individuals believe they have the skills and abilities necessary to perform their work well.

"I trust that I have the competencies to perform well"

(Spreitzer , 1995; Hernández-Marrero, 2006)

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Psychological Empowerment

Self-determination reflects a sense of freedom (responsibility or autonomy) about how individuals do their work".

"I have enough autonomy to decide how I do my work"

"I feel that I am involved in important decision-making processes"

(Spreitzer , 1995; Hernández-Marrero, 2006; Martins Pereira, 2011)

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Psychological Empowerment

Impact describes a belief that individuals can influence the system in which they are embedded.

"I have a lot to say in my workplace"

"My work has an impact in other people's lives"

(Spreitzer , 1995; Hernández-Marrero, 2006; Martins Pereira, 2011)

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Psychological Empowerment

Trust - A sense of security

"I trust that my colleagues care about my wellbeing"

(Mishra, 1992; Hernández-Marrero, 2006)

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How do we enhance ethico-clinical decision-making in palliative and end-of life care?

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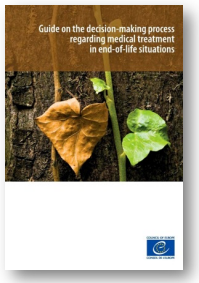
A few tools…

DELiCare



A Framework for Ethical Decision Making

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Guideline

NSW GOVERNMENT

End of Life Care and Decision-Making

Summary The Guideline is particularly relevant for situations where the patient may lose decision-making capacity before their wishes have been determined. It is intended to provide useful advice for NSW Health staff about a process for negotiating end of life decisions. It also contains information on specific issues such as children and young people, artificial hydration and nutrition, and Advance Care Directives. The Guideline also recommends minimum standards for documentation of decisions about withholding, or withdrawal of, treatment, and dispute resolution for patients, families and staff.

and many more.

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Foundational dimensions and principles of palliative care

- Holistic approach
- Symptom control
- Communication
- Psychosocial and spiritual care
- (Interdisciplinary) teamwork and Shared Decision-making

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Foundational dimensions and principles of palliative care

- A caring attitude
- Consideration of individuality
- Compassion
- Respect
- Kindness
- Vulnerability
- Exchange and honesty

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