

Welcome!

We will begin momentarily

The Oyster Care Model

Nurturing a Patient-Centered Healthcare System



Host: Diana Vincze

Presenters: Dr. Loïc Moureau and Dr. Ilse Decorte

Date: June 27, 2023

Territorial Honouring



The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness and their families.

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The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by the CFPC and Royal College.



Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Welcome & Reminders

- Please introduce yourself in the chat! Let us know what province you are joining us from, your role and your work setting
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the chat function to ask questions and add comments throughout the session
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.

Disclosure

Relationship with Financial Sponsors:

Pallium Canada

- Not-for-profit
- Funded by Health Canada

This program has received financial support from:

- Health Canada in the form of a contribution program
- Generates funds to support operations and R&D from Pallium Pocketbook sales and course registration Fees

Disclosure

Mitigating Potential Biases:

- The scientific planning committee had complete independent control over the development of course content.

Host and Presenters:

- Diana Vincze: Nothing to disclose.
- Dr. Loïc Moureau: Has received grants from Bijzonder Onderzoeksfonds KU Leuven (BOF) related to research regarding ethics, palliative care and psychiatry.
- Dr. Ilse Decorte: Nothing to disclose.

Introductions

Host:

Diana Vincze

Palliative Care ECHO Project Manager, Pallium Canada

Presenter:

Dr. Loïc Moureau

PhD student, RUPET, KU Leuven (Belgium)

Ethicist, VZW Gezondheidszorg Bermhertigheid Jesu (Belgium)

Dr. Ilse Decorte, MD

General Practitioner and Doctor in Palliative Care

Support Team

Aliya Mamdeen

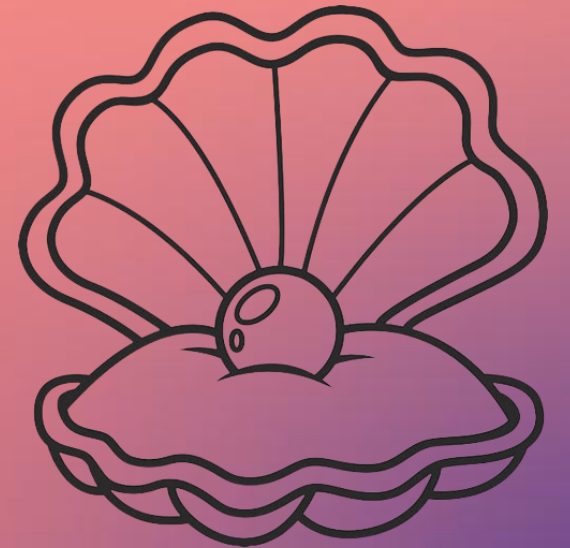
Program Delivery Officer, Pallium Canada

Diana Vincze

Palliative Care ECHO Project Manager, Pallium Canada

'Oyster Care'

A palliative care approach for people with a severe and persistent mental illness.



On the crossroads of psychiatry and end-of-life care: 5 encounters



Patients in a palliative stage who develop psychiatric symptoms (anxiety, depression, delusions,...)

Psychiatric patients dealing with life-threatening conditions (e.g., cancer)

Patients with a psychiatric disorder who enter a terminal phase because of this specific disorder (e.g. refractory forms of anorexia nervosa or chronic suicidality)

Persons requesting euthanasia or other forms of medically assisted dying, due to unbearable and incurable mental suffering (Reakiro)

Persons with severe, persistent psychiatric illness who have ‘no treatment options left’ (futility) and also enjoy little quality of life (‘palliative care approach’ – implementations of a ‘palliative philosophy’)

Origins of the concept 'oyster care'

- **Dr. Ilse Decorte**, general practitioner, specialised in palliative care at the Public Psychiatric Hospital Geel
 - Target group: patients with a severe and persistent mental illness (SPMI), often with somatic comorbidity
- **Dr. Françoise Verfaillie**, psychiatrist
- **Forum 'end-of-life and psychiatry'** (Federation Palliative Care Flanders)



Meaning of the concept 'oyster care'

- Palliative care: 'pallium' (cloak)
- Crustatieve zorg: 'crusta' (shell)
- Similarities with 'regular' palliative care:
 - Futility, risking of both negligence or over-treatment
 - Focus on making suffering more tolerable & harm reduction
 - To improve the quality of life as the main focus of care
 - Helping to build/maintain a meaningful existence
 - Supporting the mourning processes
 - Highly complex and creative care
 - Holistic care
- Caveat: the word 'palliative care' has connotations 'with giving' up and the dying process

Origins of the concept 'oyster care'

Oyster care offers an answer to the care needs of patients with a serious psychiatric illness who appear 'to have no more valid treatment options left', who suffer from severe mental illness, for whom Recovery (as societal rehabilitation) is not feasible, who need permanent intensive treatment, and who are in danger of being forgotten by the government as within the healthcare system.

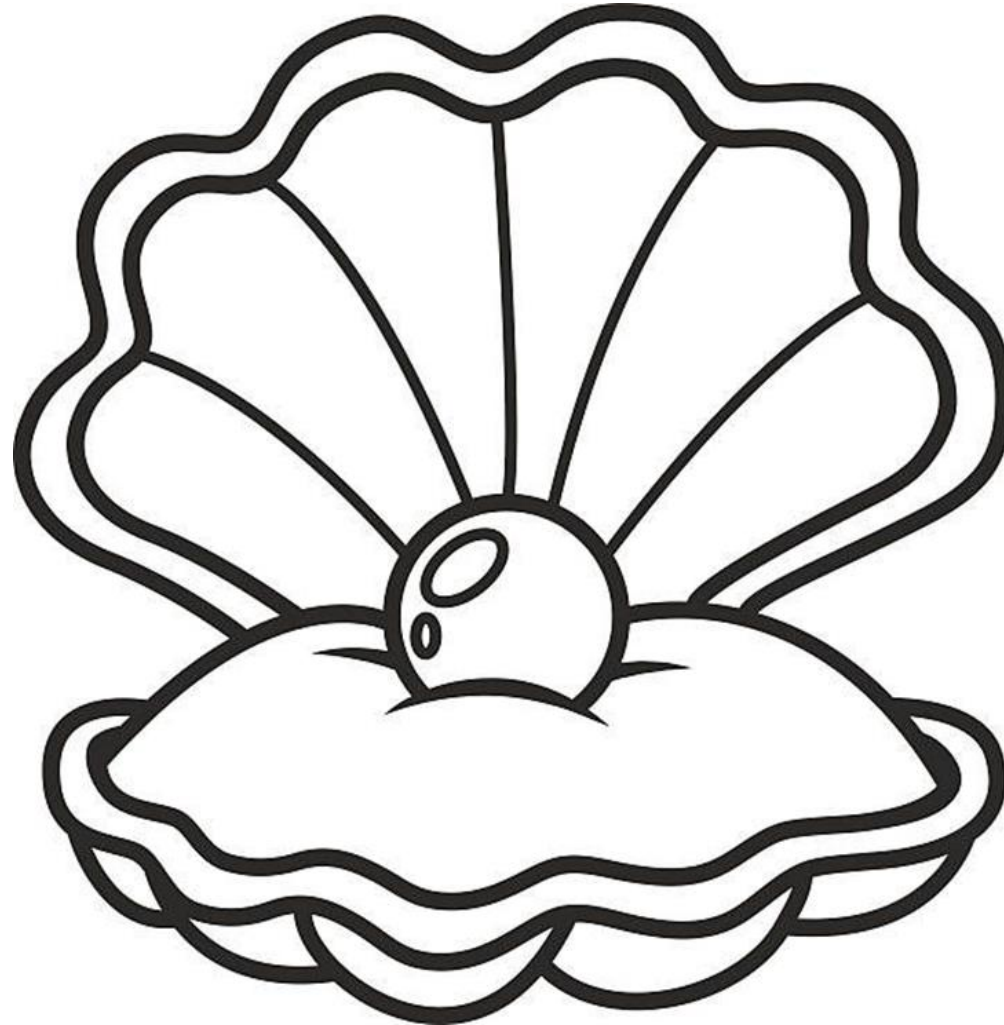
Parallel to the development of regular palliative care, there is also a place for 'palliative psychiatry', alongside curative and recovery-oriented treatment.

Meaning of the concept 'oyster care' (2)

'Crusta' means shell: “we **protect** these people with a shell in which they know themselves safe. At the same time, the term refers to the care-unit in the hospital, which, like an external skeleton, gives **meaning and structure** to these patients, who do not have sufficient strength for themselves ”(Dr. Decorte)

“Oyster care is a **dynamic approach** that responds to the needs, possibilities and pace of each patient: within the security of the shell, people can shelter, or take new steps: the shell can open itself a bit more or a bit less, depending on the current situation” (dr. Verfaillie)

How the shell became an oyster: an anecdote



Pillars of Oyster Care

Oyster care or shell care is a form of psychiatric palliative care.

It is a 'total care', based on 4 pillars:

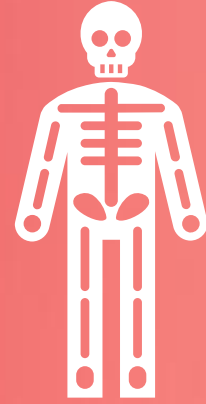
- The somatic pillar
- The mental pillar
- The social pillar
- The existential pillar



Story of Liz

- A history of long admissions, different hospitals and wards
- 66 years old
- A lot of behavioral problems and now more and more regression
- She cramped her muscles 'I can't'
- She began to fall
- Reason?
- A lot of fractures
- She neglected the fractures: did not report any symptoms of pain
- Resist to any form of help
- Another fall resulted in a spinal fracture
- We decide to fixate her
- One to one approach with focus on wellbeing
- After 6 weeks: less behavioral problems, no more falling, less suffering, a lot more wellbeing

The Somatic Pillar



The Somatic Pillar

- **Shorter life expectancy** (10-20 years compared to general population).
- Somatic **comorbidity**, linked to psychopathology, its treatment and lifestyle.
- **Unhealthy lifestyle**, long-term neglect of self-care.
- Increased risk of choking or suffocation ('fast food syndrome').
- **Limited access** to somatic treatment and follow-up treatment, due to psychiatric issues (stigma, siloing,...).



The Somatic Pillar (2)

- **Physical signals are often not adequately interpreted by the patient himself or the caregivers.**
- Symptoms are more easily interpreted as behavioral problems or psychosomatic symptoms of psychiatric the patient.
- **Pain and physical complaints are expressed and experienced differently**, and often go not recognized and under-treated.
- Different bodily experience with a different pain experience

The Somatic Pillar (3)

Focus in oyster care:

- Good somatic care and treatment, individually, tailored to the patient, e.g. close collaboration with **general practitioner**.
- In-time **recognition** of physical complaints the integration of somatic and psychiatric treatment in the treatment of 'total' pain.
- Care for meals (1 on 1 supervision).
- **Psycho-pharmacological therapy: continuous follow-up** and evaluation; maintain a good balance between treating symptoms and limiting side effects.
- The care unit works as a shell: it tries to preserve the physical integrity

The Mental Pillar



Mental Pillar

- Major **psychological frailty** due to:
 - High sensitivity to stress
 - Serious information processing disorders (attention, thinking, memory) => strong hypersensitivity to overstimulation
 - Serious problems with the processing of stimuli and the regulation of stress
 - Serious discomfort because of delusions, hallucinations, agonizing thoughts, negative emotions
 - Limited illness insight



Mental Pillar (2)

- Limited ability to introspection and mentalization
- Reduced problem-solving capacity
- Reduced emotion regulation and behavioral control
- Negative self-image and disturbed body experience

- Major psychological insecurity in contact with others (due to severe trauma, severe attachment problems) => serious difficulties to build up a relationship of trust.

Mental Pillar (3)

Focus in oyster care:

- **Being patient and persistent** in finding ways to build a positive relationship with the patient
- Continue to offer the patient the chance to attach himself to the caregivers at his own pace
- Persevere in assisting the patient in a **creative** way that is unique to each patient
- Striving for an optimal supply of contact and stimulus level
- Striving to maintain a good **balance between distance** (letting go, giving space, self determination) **and proximity** (structuring, holding, limiting)

Mental Pillar (4)

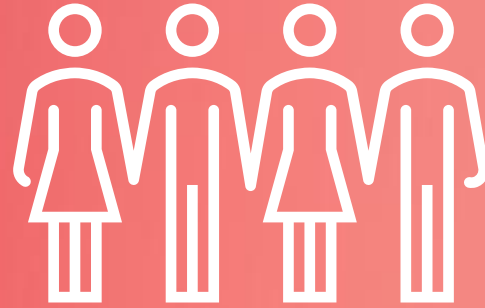
Focus in oyster(2):

- Being present (attention, dedication) (*Andries Baert*).
- Having a good view of the patient's way of communicating and the meaning of often non-verbal signals.
- Trying to sense and understand what can not be said or experienced, but is expressed in 'strange' or 'unwanted' behavior.
- **Role of the care provider:** the care provider offers 'from his person' (emotional) safety and structure that makes connection with the patient possible (*remark: risk of transgression of boundaries from both sides!*).
- The importance of a good therapeutic attitude.

Mental Pillar (5)

- Importance of a good therapeutic attitude: keywords are ‘holding’ and ‘containment’= supporting, providing support, being emotionally available, being reassuring in combination with setting protective limits.
- ‘**Positive risk taking**’: maximizing shared responsibility, applying coercion as a last resort.

The Social Pillar



Social Pillar

- **Limited social network**, isolation
- Hospital = home; important and meaningful bond with caregivers
- Serious communicative and social difficulties
- ‘Mourning processes’ regarding close relatives
- The contact with society is interrupted: “they stay inside because it hurts outside” (Doortje Kal)



Social Pillar (2)

Focus in oyster care

- Helping patients reconnect with others
- Creating a reliable environment or 'exoskeleton'
- Creating opportunities to meet other people
- Recognizing, respecting and enduring being alienated and being different (as long as it remains safe)
- **Role of the care provider:** ensuring recognisability and predictability (daytime program) and being available in a sensitive and respectful way; continue to invest in being a 'social role model'; investing in the care for relatives and friends; to recognize lifelong commitment and emotional support

Social Pillar (3)

Focus in oyster care (2):

- Social rehabilitation not as a goal in itself
- Support patients in their desire to belong and to be of significance
- Against exclusion, stigma and marginalization: in the care unit, in the hospital, in society; working towards a place of their own
- **Role of the care provider: bridge-builder** between the patient and the world around him

Story of Robert

- 52 year old
- Autistic man with severe behavioral problems
- Drinks a lot of coffee and spills a lot of coffee at the floor
- 'Coffee swimming pool'
- Eats cigarettes (picks up butts from the ground)
- Freedom restrictive measures leads to a loss of wellbeing (and have hardly effect)

- Oystercare: we adapt the environment to Robert instead of Robert to his environment
- He gets his coffee corner
- Coffee with milk
- The caregivers plead with other staff members to lock the rest of the coffee rooms in the rest of the bilding
- Use of methylphenidate (=off label medication: he calms down from coffee and sigarettes)

The Existential Pillar



Existential Pillar

- Confrontation with **many loss-experiences**.
- **Suffering from, and under the effects of the disease.**
- Confrontation with the frailty and the brokenness of life.
- Feelings of hopelessness, injustice, senselessness; explicit (words) and implicit (e.g. inactivity).
- Feelings of **powerlessness** (both in patients, family and caregivers).



Existential Pillar (2)

Focus in oyster care

- Being sensitive and open to existential themes (death, the meaning of life, freedom and autonomy).
- Daring to deal with and being able to deal with statements of meaning(lessness).
- **Remaining present, even when powerless.**
- Addressing power sources, such as the (often remarkable!) will to live.

Existential Pillar (3)

Focus in oyster care (2):

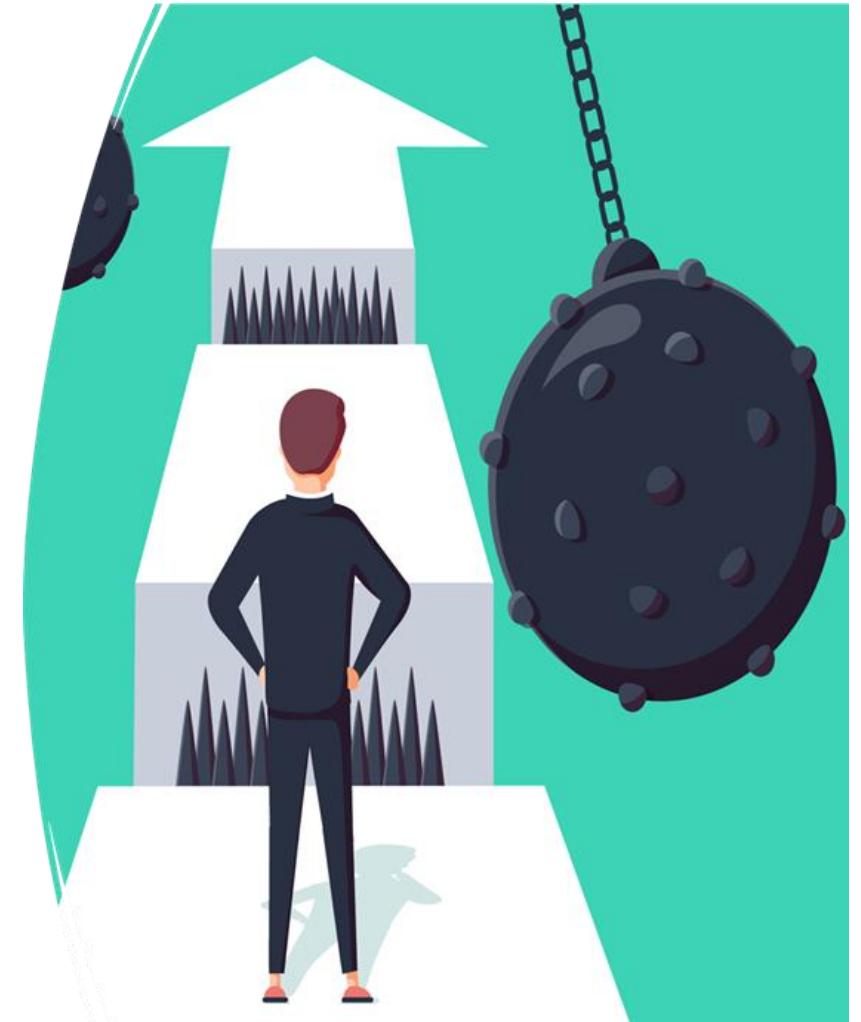
- Helping patients connect with themselves, the others, nature and the sacred in their lives, through meaningful and well-being activities.
- Searching in word and deed for the 'essence of the person', for a remaining seed of meaning and self-esteem & stimulation to let it grow.
- Care for caregivers (understanding and supporting each other from apposition of not-knowing, not-judging).

The Continuous Development Of A New Care Model



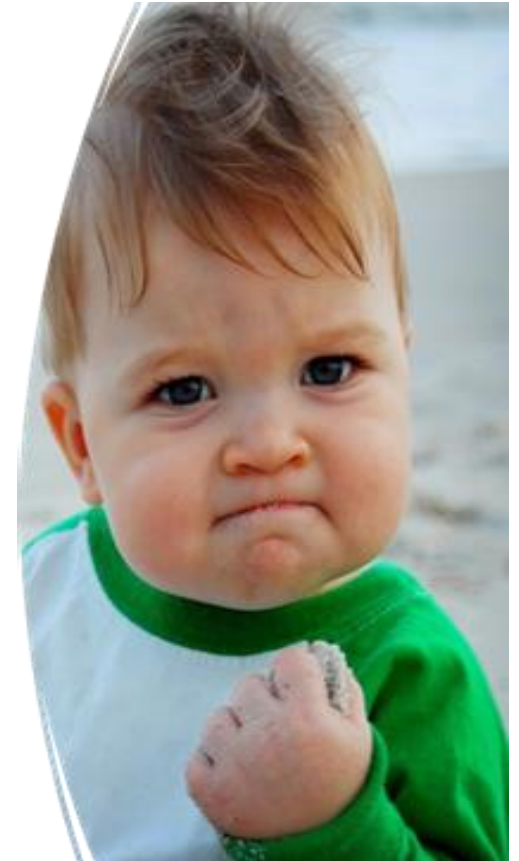
Future Goals and Obstacles

- The structural recognition, expansion and implementation of oyster care units.
- Studies regarding care actual complexity.
- Oyster care as an alternative for people with a demand for euthanasia?
- Expansion and implementation scientific research.
- Training and recruitment.
- Continuous caution regarding ethical aspects of care (coercion, DMC,...).
- ...

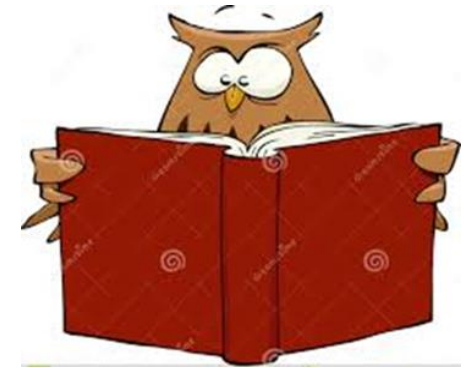


Some Milestones and Achievements

- Publications in local and international literature.
- 'Forum crustatieve zorg' (consultation, intervision, logo, website, networking, awards, television series).
- 'monitor crustatieve zorg' (a working tool and quality indicator for caregivers).
- Intensification Scientific research regarding and with the target group.
- **Appreciation and recognition of the complexity of care and the role of caregivers!**

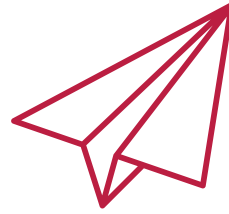


Further Reading



- Website: <https://www.crustatievezorg.be/>
- Artikel Frontiers:
<https://www.frontiersin.org/articles/10.3389/fpsy.2020.00509/full>
- Artikel TvGG: <https://tvgg.be/nl/artikels/schelpzorg-een-palliatief-zorgmodel-voor-pati-nten-met-een-ernstige-persisterende-psi-chiatrische-aandoening>
- ART: <http://art-psy.nl/het-model/>
- Reakiro: <https://reakiro.be/>

Contact Information



Dr. Loic Moureau

Email: loic_moureau@hotmail.com

Dr. Ilse Decorte

Email: decorte_ilse@hotmail.com

Q&A



Session Wrap Up

- Please fill out our feedback survey, a link has been added into the chat.
- A recording of this session will be emailed to registrants within the next week.
- Thank you for your participation during this series!

Thank You



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