

*ORGANIZACIÓN DE LA ATENCIÓN  
EN CUIDADOS PALIATIVOS.  
INTEGRACIÓN Y COORDINACIÓN  
ENTRE DISTINTOS ÁMBITOS ASISTENCIALES*

Elena Escobar Sánchez.

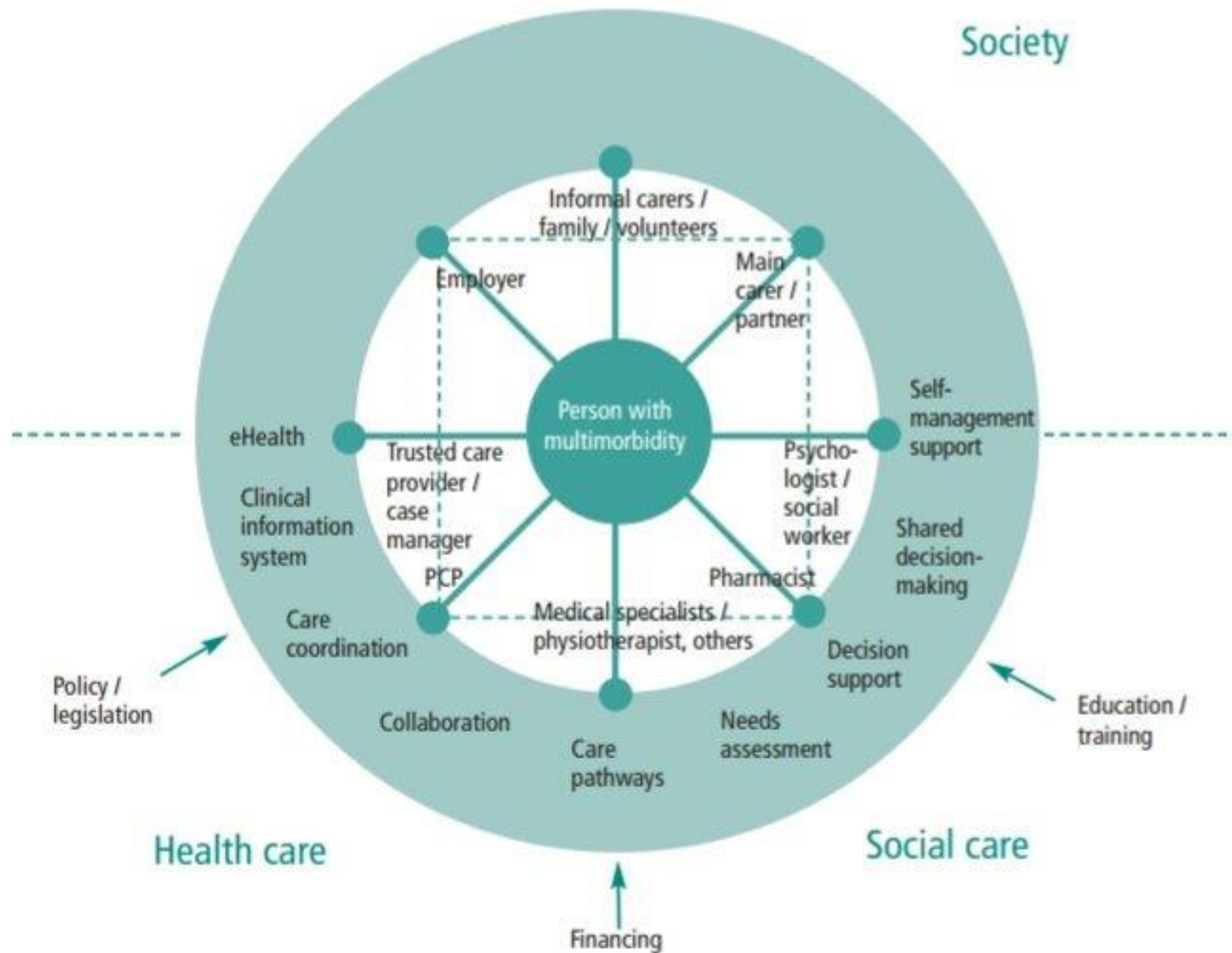
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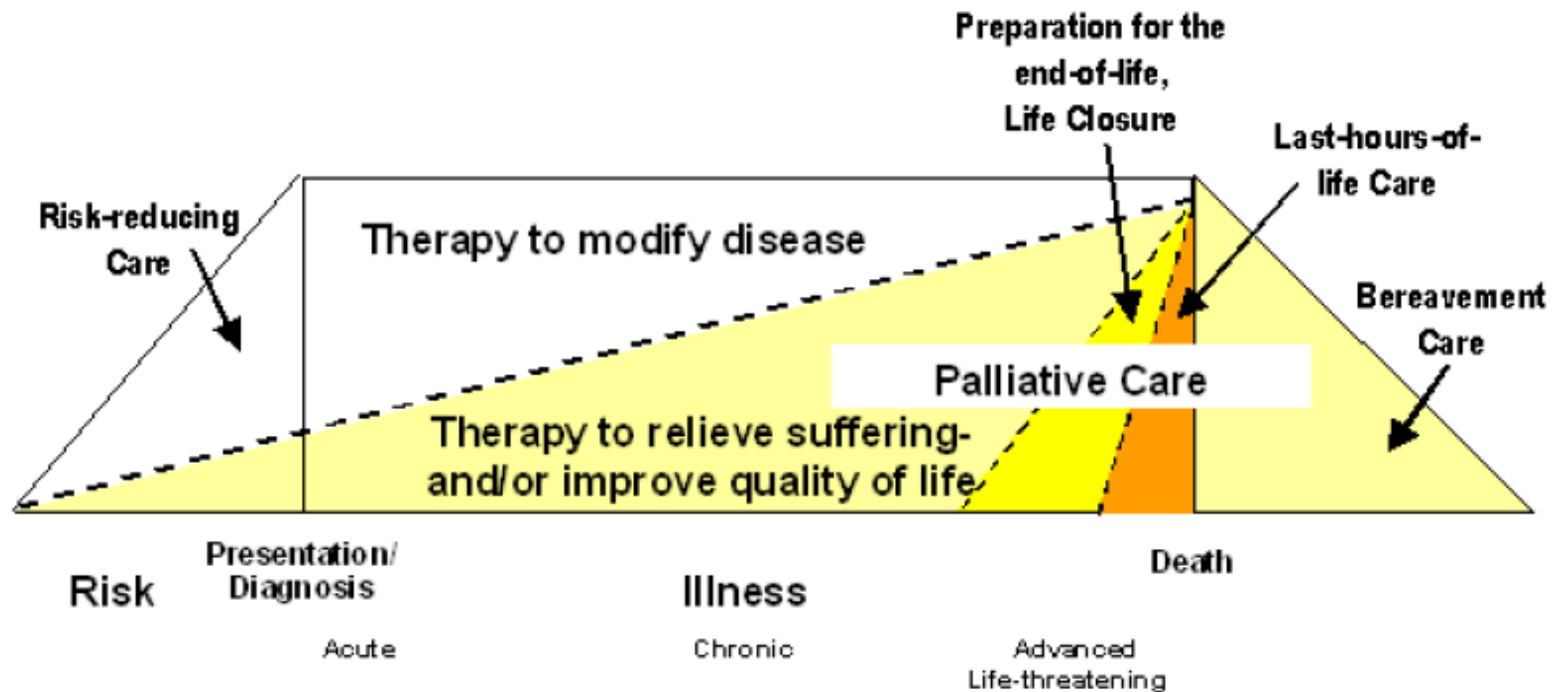
Elías Sánchez Lechuga

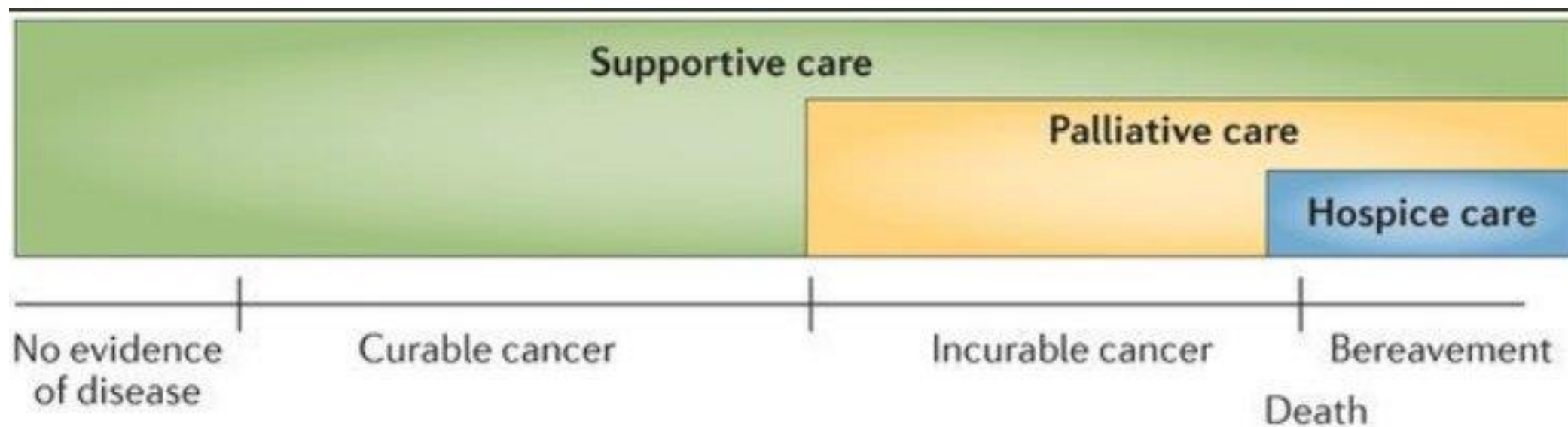
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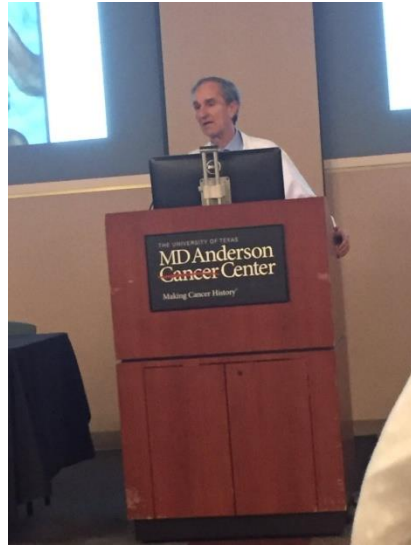
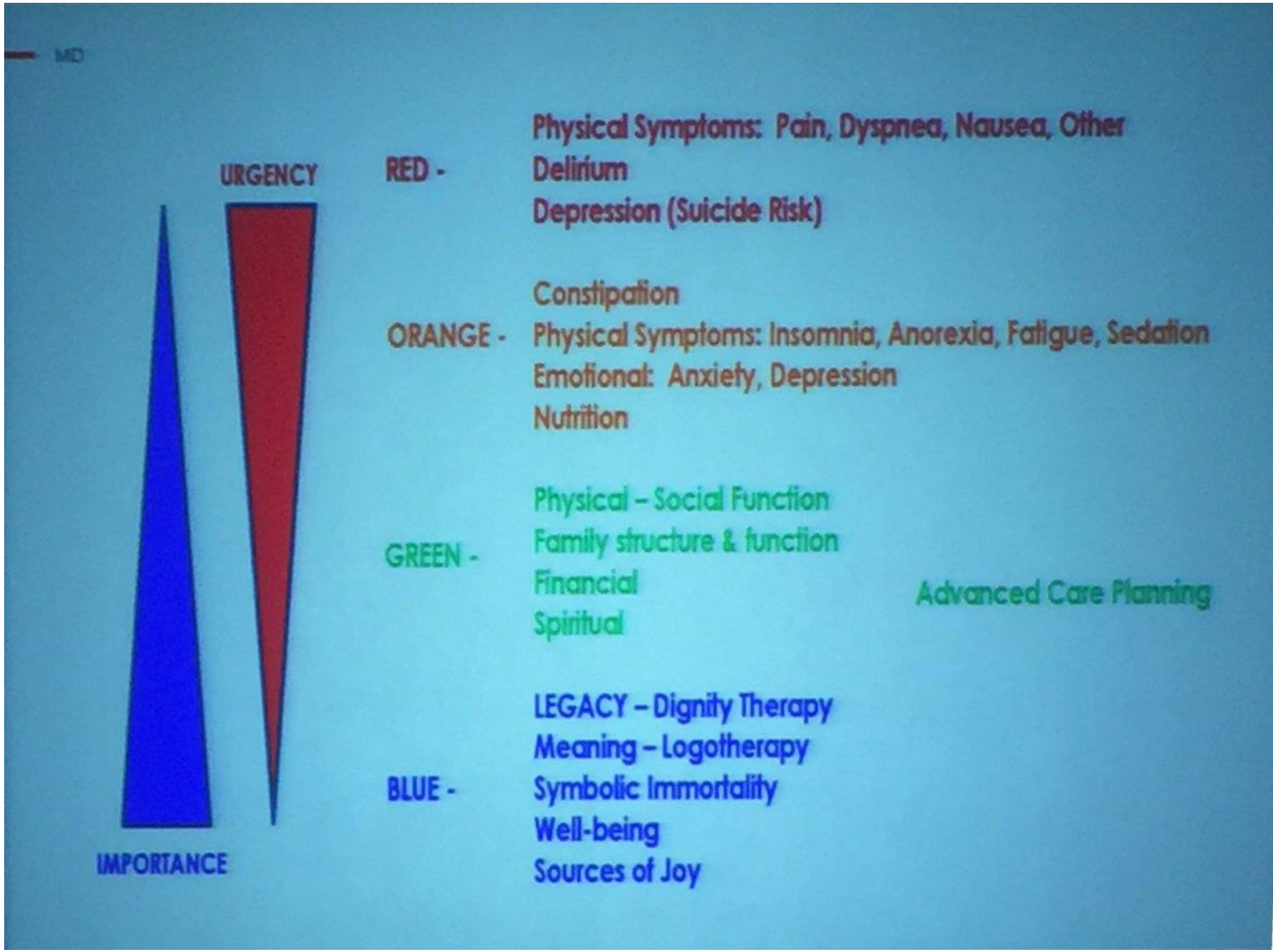
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Original Article

## Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries

Marlieke den Herder-van der Eerden<sup>1</sup>, Jeroen van Wijngaarden<sup>2</sup>, Sheila Payne<sup>3</sup>, Nancy Preston<sup>3</sup>, Lisa Linge-Dahl<sup>4</sup>, Lukas Radbruch<sup>4</sup>, Karen Van Beek<sup>5</sup>, Johan Menten<sup>5</sup>, Csilla Busa<sup>6</sup>, Agnes Csikos<sup>6</sup>, Kris Vissers<sup>1</sup>, Jelle van Gorp<sup>1</sup> and Jeroen Hasselaar<sup>1</sup>

Palliative Medicine

1–12

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DOI: 10.1177/0269216318758194

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### Abstract

**Background:** Integrated palliative care aims at improving coordination of palliative care services around patients' anticipated needs. However, international comparisons of how integrated palliative care is implemented across four key domains of integrated care (content of care, patient flow, information logistics and availability of (human) resources and material) are lacking.

**Aim:** To examine how integrated palliative care takes shape in practice across abovementioned key domains within several integrated palliative care initiatives in Europe.

**Design:** Qualitative group interview design.

**Setting/participants:** A total of 19 group interviews were conducted (2 in Belgium, 4 in the Netherlands, 4 in the United Kingdom, 4 in Germany and 5 in Hungary) with 142 healthcare professionals from several integrated palliative care initiatives in five European countries. The majority were nurses ( $n=66$ ; 46%) and physicians ( $n=50$ ; 35%).

**Results:** The dominant strategy for fostering integrated palliative care is building core teams of palliative care specialists and extended professional networks based on personal relationships, shared norms, values and mutual trust, rather than developing standardised information exchange and referral pathways. Providing integrated palliative care with healthcare professionals in the wider professional community appears difficult, as a shared proactive multidisciplinary palliative care approach is lacking, and healthcare professionals often do not know palliative care professionals or services.

**Conclusion:** Achieving better palliative care integration into regular healthcare and convincing the wider professional community is a difficult task that will take time and effort. Enhancing standardisation of palliative care into education, referral pathways and guidelines and standardised information exchange may be necessary. External authority (policy makers, insurance companies and professional bodies) may be needed to support integrated palliative care practices across settings.



#### Core team

- Includes physicians and nurses who (or some of them) are palliative care specialists.
- In many cases the core team also includes a number of other HCPs (e.g. spiritual caregiver, psychologist, social worker, or physiotherapist, occupational therapist, etc.).
- HCPs in the core team are often from the same institution and meet each other on daily or weekly basis, e.g. in multidisciplinary team meetings (MDTs).
- Within the core team standardised protocols and guidelines for providing palliative care and transferring information are often used.
- Includes HCPs that initiated the IPC initiative and who share a proactive multidisciplinary palliative care vision which they strongly aim to integrate into regular care. To achieve this aim, they depend on collaboration with HCPs in the extended professional network and wider professional community.

#### Extended professional network

- Often involves GPs, as well as individual hospital specialists. In some initiatives also other HCPs are involved e.g. palliative care nurses, community matrons, specialised heart failure nurses, social workers, physiotherapists, occupational therapists.
- Some HCPs from the extended professional network are trained in palliative care.
- Collaboration with the core team is on occasion and not standardized by means of protocols or pathways.
- HCPs from the extended professional network and core team do not meet each other on a regular basis and they are often not part of regular MDTs.
- Individual HCPs from the extended professional network work together with the core team, because:
  - o they share values: they endorse a proactive multidisciplinary palliative care approach and therefore recognize the need to work together with the core team, or
  - o they have developed a trusted relationship with HCPs from the core team, or
  - o they once heard about the additional value of involving palliative care (professionals) and therefore they are willing to work together with the core team.
- The border of the extended professional network is permeable: all those from the wider professional community who are willing to work together can become involved.

#### Wider professional community

- Mainly involves hospital specialists and GPs, but also other professional domains. (Wider community could also mean healthcare professionals within the same institution).
- Involves individual professionals who do not work together with the core team, because:
  - o their working culture is based on curing which does not provide room for (timely) palliative care, or
  - o they do not have palliative knowledge, and
  - o they do not recognize the additional value of involving palliative care (professionals)
- HCPs in the wider professional community could easily become part of the extended professional network, i.e. when they become aware of the additional value of palliative care.



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# Integración basada en complejidad



### **A. Identificación en cualquier nivel asistencial y lo más precozmente posible a los pacientes susceptibles de CP**

1. Fomentar la responsabilidad de la identificación del paciente en situación de final de vida.
2. Articular mecanismos de identificación del paciente al final de la vida en cualquier contacto, incluyendo los servicios de urgencias.
3. Potenciar la detección precoz en los grupos más vulnerables (no oncológicos, niños, adolescentes, institucionalizados, etc.).
4. Fomentar la inclusión de alertas específicas que identifiquen o sugieran a pacientes susceptibles de CP en la historia clínica electrónica.
5. Fomentar la utilización de los códigos específicos de la CIE para diagnósticos relacionados con CP (V 66.7 en la CIE9MC).
6. Realizar una primera estratificación en función de los factores de complejidad descritos

### **B. Elaboración de un Plan de Atención Individualizado**

1. Elaboración del Plan de Atención Individual (PAI) como elemento clave de la historia que recoja la evaluación integral de las necesidades del paciente y su familia.
2. Facilitar la toma de decisiones favoreciendo la participación del paciente y su familia según sus necesidades, deseos, valores y preferencias y de acuerdo a estándares de una asistencia de calidad al final de la vida.
3. Promover información sobre el documento de Voluntades Anticipadas.
4. Revisión periódica del PAI adecuándolo a las necesidades evolutivas, especialmente en los últimos días.
5. Fomentar el trabajo interdisciplinar y en equipo.
6. Desarrollar mecanismos de gestión y transmisión de la información.
7. Favorecer la formación básica en CP de los profesionales sanitarios.

### **C. Garantizar la continuidad asistencial**

1. Organización de recursos para garantizar asistencia las 24 horas del día.
2. Promover actividades para mejorar la coordinación entre los diferentes recursos asistenciales.
3. Favorecer recursos de cuidados paliativos avanzados en hospitalización de crónicos y de larga estancia.
4. Disponer de recursos necesarios para prestar los CP a las personas institucionalizadas.
5. Establecer una coordinación entre servicios sanitarios, centros sociosanitarios y recursos sociales.

## Equipo de soporte en Cuidados Paliativos Hospitalario

Recibe a pacientes derivados de otras unidades hospitalarias y adecua sus orientación diagnóstico-terapéutica hacia los cuidados paliativos. En algunas ocasiones el diagnóstico de terminalidad es reciente, precisando adecuar la información, modular el impacto y realizar una propuesta de abordaje paliativo dentro del hospital y posteriormente fuera de él. En otras asume o colabora en el abordaje paliativo del caso desde una mirada interdisciplinar buscando adecuar el sistema sanitario a las necesidades globales del paciente y su familia promoviendo la coordinación con otros recursos intra y extra-hospitalarios. Realiza además formación, docencia e investigación. Su posición en la hospitalización de agudos le provee de todos los recursos y toda la tecnología al alcance de nuestro sistema.

### Funciones:

- Atender y/o coordinar la atención de los casos diagnosticados en el ámbito hospitalario

### Actuaciones específicas:

- Valoración integral de casos nuevos
- Resolución de interconsultas de pacientes no a su cargo
- Asesoramiento telefónico a profesionales
- Coordinación con otras estructuras (servicios sociales, hospitales de media larga estancia, hospitales de agudos...)
- Cooperación en el seguimiento especialmente de los casos de mayor complejidad
- Seguimiento en consultas externas de pacientes compartidos con otras especialidades (Neurología, Cardiología, Neumología etc.)". Es un trabajo añadido y que aporta especificidad al equipo, al intervenir de forma más precoz en algunas enfermedades tipo ELA, Fibrosis pulmonar, insuficiencia cardiaca, etc.
- Atención directa integral e interdisciplinar a pacientes a su cargo
- Formación Continua en el ámbito hospitalario
- Investigación y Docencia

