

# Transitions in palliative care and its meaning for people at end of life

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# Outline of the Presentation

- Background and Problem
- Methods
- Findings
- Conclusions and Implications for practice



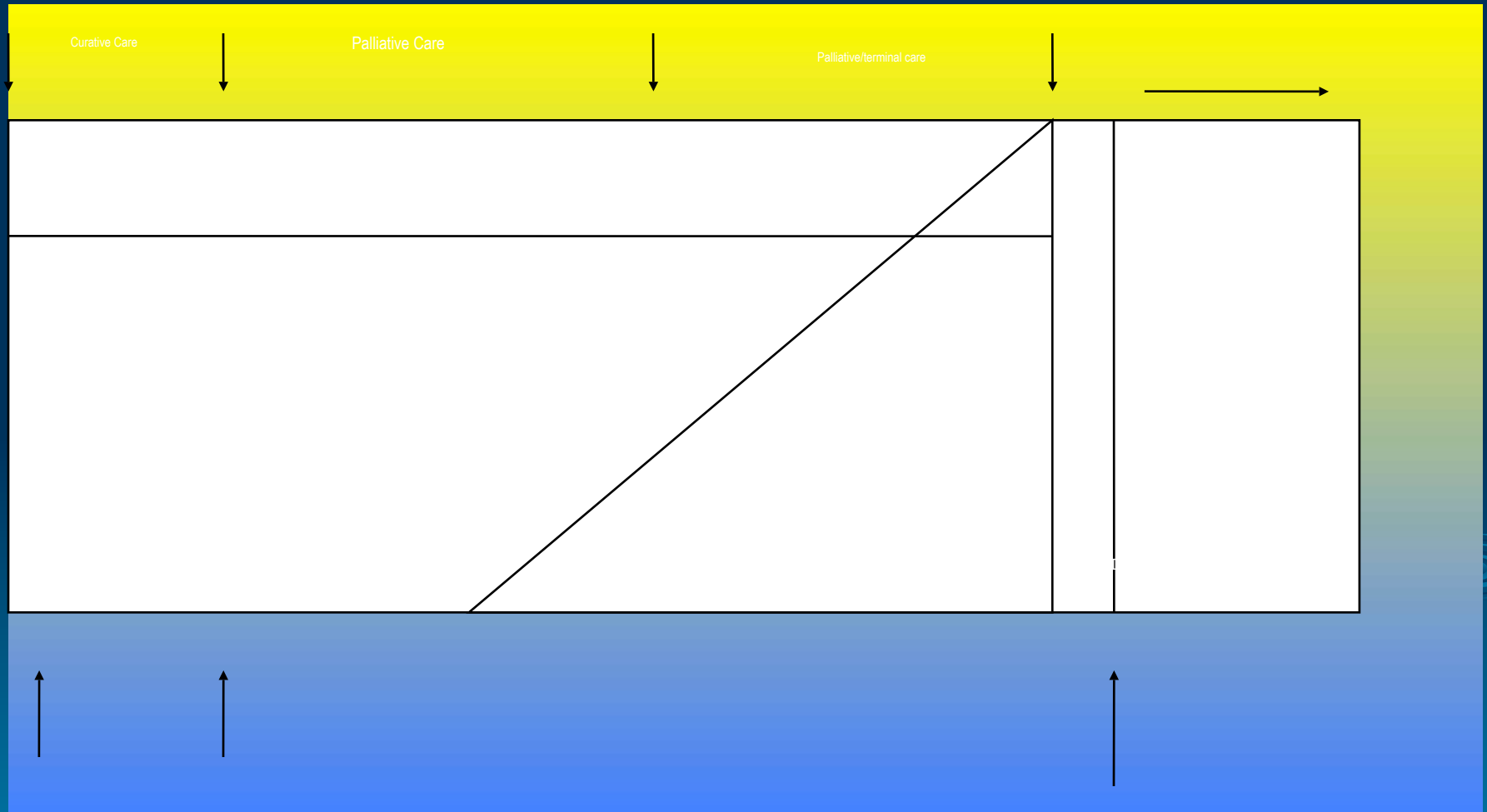
# Background to problem

- *“..when someone refers to palliative care, it is unclear how he [sic] appreciates it, because the use of term in itself is not sufficient to clarify the position he or she has with respect to supporting the dying”*

( Illhardt, 2001, pg 110)



# Transition towards palliative care (Krakowski *et al.* 2004)



# Study rationale

- Palliative care- as set of common principles amidst differing practices, frameworks and outcome measures.
- Weak descriptions of transition in relation to palliative care
- Limited evidence of patient experiences



# Objectives of the Study

- To describe advanced cancer patients experiences of the transition to palliative care.
- To categorize supportive and limiting factors they experience during transition.
- To describe the impact of this transition on patients expression of their end-of-life – palliative/terminal phase.



## Comparison of EU Palliative Care Services

Country	Total number of adult Palliative Care Services	Total number of In-patient palliative care Units/Hospice beds	Overall % of palliative care patient population with advanced cancer ( estimated)	Predominant funding source (Public & Charitable)	Key challenge for the future
United Kingdom ( UK)	881	2515	95%	Both	Augment a diminishing workforce
Ireland ( IRL)	49	147	95%	Both	Address structural deficiencies
Spain (Es)	287	883	95%	Public	Seek political commitment
Netherlands (NL)	128	346	80%	Public	Ensure quality of new services
Italy (I)	258	1095	60%	Public	Seek academic recognition
Switzerland (CH)	37	NK	NK	Both	Raise awareness

NK = Not Known.

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# Patient Criteria

- Advanced cancer diagnosis with clinical prognosis of 6-9 months
- Able to consent verbally and in writing ( No cognitive impairment)
- Aware of diagnosis and prognosis
- Able and willing to share their experience.



# Methods: Sample

Country	Final Sample	Male patient	Female patient	Mean age Overall (range)	Life Expectancy Post interview in days	Research Centres
<b>U.K.</b>	20	8	12	72.9 (55-92 years)	41.8	2 Hospices
<b>IRL</b>	20	10	10	72.8 (49-87 years)	37.6	1 Hospice
<b>NL</b>	15	5	10	75.8 (50-91 years)	40.5	1 Hospice
<b>I</b>	18	5	13	59.6 (45-81 years)	48.4	1 Hospital Palliative Care Centre
<b>ES</b>	10	9	1	64.1 (45-84 years)	32.5	1 Hospital Palliative Care Centre
<b>CH</b>	17	8	9	79.8 (55-92 years)	38.5	1 Hospice 1 Palliative Care Centre
<b>Total</b>	<b>100</b>	<b>45</b>	<b>55</b>	<b>70.83 years</b>	<b>39.88 days</b>	<b>8 centres</b>

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# Methods: Semi-Structured Interview

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# Methods: Semi-Structured Interview

- Examples of clinical change which led to the cessation of curative treatment
- Introduction to palliative care.
- Transition towards end-of-life.
- Supportive and inhibitory factors.



# Methods: Semi-Structured Interview

- Examples of clinical change which led to the cessation of curative treatment
- Introduction to palliative care.
- Transition towards end-of-life.
- Supportive and inhibitory factors.
- The impact of this transition on the patient.



# Substantive, Evocative and Affirmative Stages of Analysis

108 codes  
Atlas.Ti.

## Substantive stage

6 codes

Clusters of  
related codes

Creates 11  
themes

## Evocative stage

Descriptive  
statement per  
country

Reflect  
"lifeworld  
existentials"

Four impact  
examples

Four patient  
responses

## Affirmative stage

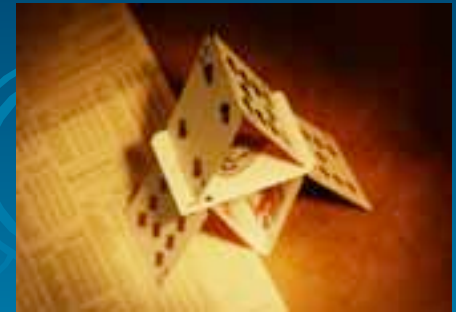
Critical referent  
group at each  
stage

Dialog with  
translators and  
interpreters

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# Stability and security

- *“Well, probably at the time I was feeling worn out. I was lying in that bed really, really like a broken person and was thinking that [transfer to a hospice] actually sounds too good to be true” ( NL # 2).*
- *“ I didn’t know what it was [palliative care]..no one told me anything.. it’s very, very difficult; you can’t imagine what it’s like...Because when I arrived here I was (silence) how can I ...lost? I felt really lost”.(CH # 3)*



# Spatiality

- *“ I am at home here..even when I went out to celebrate my birthday, I was a stone’s throw from the house, we went past it. I didn’t even stop. What for? To go up the stairs with great difficulty and then come down again a quarter of an hour later..I didn’t need to...what would I have done..checked for dust?” ( CH # 13).*



# Temporality

- *“I don’t have many requests. My time has come. To lament now I am going? No, as far as that is concerned I have had my time”. [NL #6]*
- *“Monday, the GP came and said: listen, they have room for you. And they would be on the doorstep on Tuesday morning at 9 or 10 am. But you have to take care of things. You can’t just leave like that, you have bills, you have this, you have that..( NL#6)*





# Relationship

- *“..this [hospice] has helped more than my whole family. I’ve felt free to talk about things and say- that they may not even understand. They don’t understand the disease, they don’t understand me, they don’t understand anything [crying]”.(SP #5)*
- *“I had somebody share my room, I noticed all the care until she passed on and I thought, well, that’s very, very comforting because it will happen to us. I missed her. I felt very close to her and when she went I thought..I know its horrible.. but I wish she could stay”. ( UK # 20)*

# Key Factors

- Palliative care professionals become increasingly meaningful to patients.
- Lack of visibility in general healthcare settings is a concern.
- The need for forward planning is a need for patients at this time.



# Reflections

- Does transition as currently described in the literature fit the experiences of this group of palliative care patients?



# Case 1, Elizabeth

- 58 year old woman
- Astrocytoma Grade IV with marked incapacity.
- Lived with her partner and his three children for 11 years.
- Partner requested her to leave their home as he was no longer able to care for her and the children.



# Case 1, Elizabeth

- *“This last relapse has been a big one, but I always knew that each one was going to be worse than the one before. I’ve lost a lot, mobility, home, relationship. I look back and see if somebody’s not letting you die they’re also not letting you live...and I do want to live, I want to live and enjoy until the last minute you know” ( UK #18)*



# Case 2, Margaret

- 64 year old woman
- Ca colon metastatic disease
- Late diagnosis
- Moved to be with daughter for respite care
- Family sold her home and possessions
- Admitted to hospice as 'homeless'

# Case 2, Margaret

- *'You never know someone until you live with them. Everything I knew is gone now, my husband, my home. I just want to go and be with him. I know that people act of kindness but that is often what makes it worse for me. I have nothing and no-one left any more.'*

# Transience

- transition as a “*phenomenological description of movement*” whereas transience refers to an emotional state often associated with sadness and painful feelings ( Kitayama, 1998).



# Attributes of Transience

- A sudden and unexpected change in life circumstance.
- Inability to prevent that change
- A personal shift in both time and space
- The realisation of a fragile and impermanent existence



# Considerations

- It may be that we seek transition because the hope of a positive outcome is easier to deal with than the fragility and impermanence transience offers.
- Palliative Care professionals address transience through acknowledging the immediate, rather than the future.



# The sense of being present

- Respecting courage, not fortitude
- Willingness to connect
- Being sensitive to emotional distress
- Addressing personal existential anxiety
- “Compassionate competence”

*Rawnsley MM Cancer Nursing 1994, 17(4): 342-347.*



# The need to dispel fear



- Understanding your cancer
- Knowing your carers
- Understanding the system/treatments
- Seeks support
- Addresses stressors

# Communication



- That you act out of humanity
- That you keep me informed
- Being there throughout my ordeal
- Caring about the outcome
- Respecting what is important to me

# Good Death

- “ Good death is neither protracted nor sudden, its shape constituting a straightforward trajectory from deterioration to death”.
  - Komaromy & Hockey 2001: 75

# On loneliness



“ ..people with cancer do not find it easy to ask for help and those that need it most are often least likely to access information and support”

Wells M, Kelly D. European Journal of Oncology Nursing, 2008:  
410-411.

# On finiteness



“What seemed impossible comes to seem possible. What only seemed possible becomes likely and what seemed likely is finally revealed as inevitable”

*Callahan D, Topinkova E. Age, rationing and palliative care in Morrison RS, Meier D. Geriatric Palliative Care 2003, Oxford University Press, USA*

# The need for memorial



# What seems to matter to those caring for people in their transition

- Learning valuable practice insights
- A shared search for meaning
- Bearing witness and valuing time shared
- Valuing the intangible
- Understanding the need to let go

- *Quinn B, European Journal of Oncology Nursing 2003, 7(3):  
164-171.*

# Conclusions



- “I” should be at the heart of decision-making with respect to end-of-life care, institutional structures and processes.
- If “I” reflects my autonomy and independence, “you” need to reflect my need for understanding, empathy, information and communication.