Easing the transition from curative care to palliative care

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Presentation

- My clinical practice
- Characteristics of the transition
- When should palliative care be discussed?
- Steps for discussing transition
- « Being in touch with myself »
- Clinical examples
- Conclusion
My clinical practice
My nursing practice

- Phone practice (more than 95%)
- First contact for patients referred to the palliative care out-patient clinic
  - Phone evaluation
    - Physical aspects (symptoms)
    - Level of functioning
    - Psychosocial aspects
- What do the words “palliative care” mean to you?
Answers from patients and families

« Not much longer to live. »
« Not much hope. »
« There is not much left to do. »
« Death pretty soon. »
« You go there to die. »
What I have noticed

- Palliative care = end of life care
- People are scared of the words « palliative care »
- « pain service team »
- Hiding behind words
- Perpetuating fear and misunderstanding
- Who will explain what palliative care is all about?
- Causing more pain and sorrow
« (…) the provision and implementation of palliative care into clinical care has been hindered by cultural barriers, medical reasoning with an emphasis on “cure”, and societal attitudes towards death and dying. »

(Zambrano et al, 2016)
« Palliative care is intended for all of the seriously ill, not just the actively dying. »

(Wittenberg-Lyles & Ragan, 2011)
« Unlike hospice, palliative care is not limited by prognosis and may be provided at the same time as disease-directed therapies. »

(Shin & Temel, 2013)
Characteristics of the transition
Discussing the transition from curative cancer treatment to palliative care is often difficult and stressful for both clinicians and patients. 

(Grainger et al, 2010)
Transition to palliative care

- Recognized as a difficult process
- Major clinical challenge
- Many uncertainties
- Feeling of helplessness and abandonment
- Not perceived as a way to optimize quality of life

(Duggleby & Berry, 2005; Grainger et al, 2010; Marsella, 2008; Ronaldson & Devery, 2001)
Benefits of « early » palliative care

- Improvement in symptoms
- Less depression
- Less distress
- Improved quality of life
- Satisfaction with care and communication
- Less likely to be admitted to hospital, ICU, or ER
- Less aggressive treatments
- More likely to establish advanced directives
Benefits of « early » palliative care

- Increased likelihood of dying in their preferred place
When should palliative care be discussed?
When discussing it?

- No clear consensus in the literature
- Patient fears future suffering
- Pt / family ask about hospice / palliative care
- Patient is imminently dying
- Patient talks about wanting to die (MAiD)
- Patient has severe suffering and a poor prognosis
- Symptoms poorly controlled

(Quill, 2001; Schofield et al, 2006)
« An agreement seems to be that palliative care should be integrated before patients experience burdening symptoms for the first time. »

(Zambrano et al, 2016)
Recommended steps for discussing transition from curative to palliative care

based on Schofield et al, 2006
Recommended steps

- Prior to discussion
- Elicit pt’s understanding of situation and preferences before discussing clinical decisions
- Provide information
- Respond to pt’s emotional reaction
- Negotiate new goals of care
- Continuity of care
- Address family concerns
- Acknowledgement of cultural and linguistic diversity
Recommended steps

- Concluding the discussion
- After discussion
Recommended steps

- Prior to discussion
  - Review all pertinent information (px, therapeutic options)
  - Psychosocial information
  - Private place, uninterrupted time
  - Invite pt to have family present
Recommended steps

- Elicit pt’s understanding of situation and preferences before discussing clinical decisions
  - Understanding of disease, treatments, tests
  - Determine feelings, concerns, goals
  - (quality of life)
  - (meaning of life)
  - Assess preference for information
Recommended steps

- Provide information
  - Simply and honestly
  - Using lay terms
  - Disease progression
  - Treatment efficacy
  - Prognosis
  - Symptom management issues
  - Convey information that no curative treatment exists for the disease
Recommended steps

- Respond to pt’s emotional reaction
  - Encourage expression of feelings
  - Empathy
  - Active listening
  - Wait until tears or emotional reactions subside before moving on
**Recommended steps**

- **Negotiate new goals of care**
  - Discuss further treatment options (ending treatment)
  - Provide information about the role of palliative care: symptom management and quality of life
  - Use the term « palliative care »
  - Promote holistic nature of palliative care
  - Emphasize that symptom management can be done during treatments
  - If continues to ask for curative treatment: explore
  - Reassurance and hope
  - « there is never a time when nothing can be done »
  - (Include DNR in discussion)
Recommended steps

- Continuity of care
  - Palliative care team is part of the multidisciplinary team
  - Goal is optimal care, not abandonment
Recommended steps

- Address family concerns
  - Family needs to be informed and understand the implications
  - Young children or adolescents involved?
**Recommended steps**

- **Acknowledgement of cultural and linguistic diversity**
  - Be aware of attitudes and information needs of different cultural groups
    - Prognosis, death and dying
    - Can step outside of their cultural circle (do not generalize)
Recommended steps

- Concluding the discussion
  - Summarize main points of the discussion
  - Check patient and family’s understanding
  - Written information if available
  - Need for referral?
  - Emphasize hope-giving aspects of the discussion (quality of life)
  - Questions?
Recommended steps

- After discussion
  - Share with team about discussion
  - Share with team your perception
  - Document discussion

(Schofield et al, 2006)
« Being in touch with myself »
« Not only does the health professional have to deal with patients' emotions and concerns, but potentially their own feelings of failure, helplessness and frustration arising from advancing illness. »

(Schofield & al, 2006)
Being in touch with myself

- This implies being aware of
  - My values
  - My beliefs
  - My strengths
  - My challenges
  - My goals
  - My motivations
Clinical examples
Mrs Angelica
Clinical situation

- 89 yo lady with advanced dementia
- No verbal interaction, no eye contact
- Bedridden for months
- Large pressure wound on coccyx
- 3 daughters involved in her care
- Lives with the oldest
- 2 pneumonias in the last few months requiring hospitalization for IV antibiotics
My own personal motivation

- Poor quality of life
- Prolonging an undesirable condition?
- Restraints required for IV antibiotics
- Appropriate to treat the next pneumonia?
- There is a choice
- What would she want?
- Age / diagnosis / prognosis
Recommended steps

- Prior to discussion
- Explore understanding, preferences
- Provide information
- Respond to emotional reaction
- Negotiate new goals of care
- Continuity of care
- Address family concerns
- Acknowledge cultural and linguistic diversity
- Concluding the discussion
Mr Young
Clinical situation

- 40 yo man with colon cancer and liver metastases
- Jaundiced, weak, sleepy and difficult to arouse at times
- Severe edema of lower legs
- Limited capacity to walk
- Wife on sick leave
My own personal motivation

- Poor quality of life
- Pertinent to give blood transfusion?
- Prolonging undesirable state?
- Actively dying
- Discussion needed today
- Place of death?
Recommended steps

- Prior to discussion
- Explore understanding, preferences
- Provide information
- Respond to emotional reaction
- Negotiate new goals of care
- Continuity of care
- Address family concerns
- Acknowledge cultural and linguistic diversity
- Concluding the discussion
In conclusion
Things to remember

- Adjustment to death is a process and cannot be rushed
- Needs of patient and family should be heard and honoured
- Needs should not be questioned or challenged
- Patient and family should remain in control of decision making with the team acting as guides and facilitators

(Duggleby & Berry, 2005)
Last words…

- Trust patient and family
- Do not underestimate their strengths and resources
- Courage and resilience
- Take the time to listen
- Silence
- « planting a seed »
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