Communication about death and dying in non-cancer diagnoses

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Overview

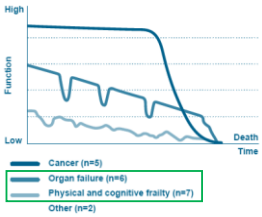
- The *problem* with non-cancer diagnoses
- Is there evidence that communication about dying and death is different in non-cancer vs. cancer?
- How good are palliative care specialists at communicating about dying and death?
- The role of palliative care specialists in training non-specialists in communication

Definitions

- Due to the limited evidence for the different types of conversations, we will consider the following to be synonymous with communication about death and dying:
  - EOL communication
  - Goals of care conversations
  - Prognosis disclosure conversations

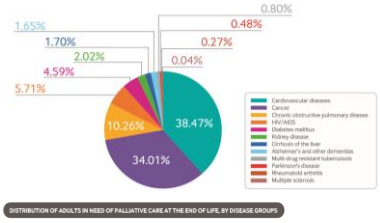
The problem with non-cancer diagnoses

An unpredictable decline



Lynn and Adamson, 2003

Needs of care vs. Access to care



DISTRIBUTION OF ADULTS IN NEED OF PALLIATIVE CARE AT THE END OF LIFE, BY DISEASE GROUPS

McIlvennan and Allen, 2016, BMJ

Further differences

- Generally older population
  - Frailty and dependence on others
  - More likely to have comorbidities
  - And thus a variety of treating physicians
    - Lack of clarity of whose role is it to initiate and continue end of life discussions
  - Disease progression is harder to identify
    - Unclear when the end of life period begins
- Symptom burden and prognosis are comparable to (or worse than) those of patients with malignancy

Further differences

- Unlike in cancer, people are unaware that most of these illnesses are life-threatening
- The prognosis can be poorer than for many cancers
  - In heart failure 38% of patients die within 1 year of diagnosis and 60% within 5 years
  - Around 50% of deaths are sudden
    - Particularly disadvantaged in ACP participation

Barclay et al. 2011

Is communication about dying and death different in patients with cancer vs. those with non- cancer diagnoses?

The importance of context

- Most palliative care studies to date focus on patients with cancer
  - Perspectives of the 'younger old' have shaped our discourse and our approaches
  - There is increasing debate as to whether an approach to end of life care based on the needs of cancer patients is appropriate
  - How is a 'good death' seen by the old-old?
    - Place of death, autonomy, individuality, open awareness of dying/death

Gott et al. 2008; Macdonald et al. 2016; Periyakoil, 2018; Pollock and Seymour, 2018

Communication in heart failure

- For some the knowledge that death could be sudden is welcomed
- Others do not wish to have these conversations
  - They prefer not to think about their prognosis
  - They do not regard end of life issues as relevant to them
  - They see their condition as part of growing old
  - They accept a low level of knowledge about their illness and prefer to leave medical issues to their professionals
- Patients are most likely to consider EOL decisions when unwell

Barclay et al. 2011

Communication in heart failure

- Even in later stages of HF the focus remained on managing everyday restrictions
- Clinicians, feel underskilled in discussing prognostic and related palliative care issues
  - Are reluctant to conduct discussions in an outpatient setting
  - Clinical interactions emphasise the 'manageable' nature of HF
  - Patients and carers take the lead from clinicians, who remain optimistic
  - Regular interactions with the clinical team offered reassurance that patients could remain stable
- HF was seen as something to be expected with advancing age

Stocker et al., 2017 BMJ Supp Pall Care

Need for more research

- Beyond organ failure, the needs of patients with frailty or dementia and their families
- Are patient and family preferences really different in this context?
- How and when to initiate end of life discussions with these groups?
- Who is the best person to initiate these conversations?
  - Stark contrast with oncology
- To what extent can palliative care specialists influence the primary care context?

How well do palliative care specialists address issues of dying and death compared to non-specialists?

The baseline

"Palliative care providers are among the best communicators in healthcare, as well as the most well practiced."

(Wittenberg et al. 2016)

EPC outcome improvement

- Symptom management
- Quality of life
- Prognostic understanding
- Caregiver outcomes
- Mood
- Survival
- Resource utilisation
- End of life outcomes

HOW DOES PC IMPROVE THESE OUTCOMES?
What is the mechanism of action?

Myles et al., 2016 ASCO

The evidence

- Patient-centered communication is fundamental to the practice of palliative care and represents a key underlying mechanism by which palliative care improves quality of life among the seriously ill

Ingerson et al. 2018

Differences between oncology and PC

- Early palliative care discussions over 68 clinic visits with 19 patients
- Length of the visit was similar
  - Oncology 24 minutes (range: 7-40 minutes)
  - Palliative care 28 minutes (range: 8-48 minutes)

Thomas et al… Temel, 2019

Differences between oncology and PC

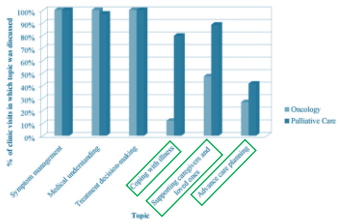


FIG. 2. Frequency of six major topics by clinician type.

Thomas et al… Temel, 2019

Differences between oncology and PC

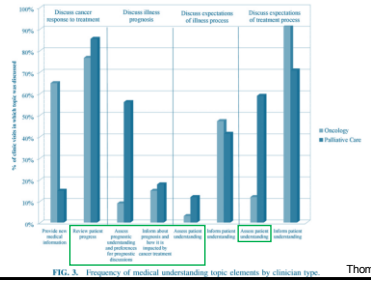
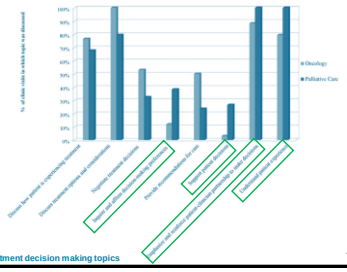


FIG. 3. Frequency of medical understanding topic elements by clinician type.

Thomas et al… Temel, 2019

Differences between oncology and PC



Thomas et al… Temel, 2019

Added value of PC consultations

- Building of supportive partnerships with patients and caregivers
- Clarifying patient's understanding of their health, prognosis and treatment
- Providing concrete coping skills to help patients and caregivers manage the illness

Thomas et al… Temel, 2019

Feeling heard and understood

- Communication Quality Among Patients With Advanced Cancer Before and After Palliative Care Consultation (n=207)

Over the past two days ["24 hours" for the post-consultation version], ***how much have you felt heard and understood by the doctors, nurses, and hospital staff?***
Completely / quite a bit / moderately / slightly / not at all

Before
- 1 in 3 felt completely heard and understood
- Those with unformed preferences for EOL treatment, or who did not know their prognosis were the least likely to feel heard and understood

After
- Among those with less-than-ideal quality at baseline, 56% rated feeling more *Heard & Understood* after PC consultation with 27% feeling completely heard and understood
- The greatest improvement was among people who had unformed end-of-life treatment preferences or who reported having no idea about their prognosis at baseline (23% to 40%).

Ingerson et al., 2018 JPSM

Need for more <u>and</u> broader research

- Even if good communicators, contexts and type of involvement need to be considered carefully
  - Initial evidence showed that consultative approaches may be better than integrative approaches, e.g. in the ICU
  - Yet, a recent RCT in the ICU found that PC-led family meetings vs. ICU-led family meetings did not reduce anxiety, nor depression, and may have increased PTSD symptoms

Carson et al., 2016; Fawole (…) Aslakson et al. 2012

Need for more and broader research

- Non-physicians may be at a disadvantage and could benefit from interdisciplinary training
  - Greater focus on physicians' communication skills development
  - Nurses, social workers, and chaplains are often present with patients and families when a diagnosis of a serious illness is delivered
    - At times they are the ones directly communicating with people when death is imminent or at important transition points

Ferrell et al. 2019

Contributing factors?

- We can speculate:
  - Covenant of care and prior relationship
  - Other aspects
    - Concrete education?
      - There is more focused training
      - Being a good communicator is the baseline
    - Interprofessional approach?
      - Shared responsibility
      - Covering *all* aspects of relevance
    - Exposure and frequency of dealing with this situation?
    - Supervision and reflection?

Sinuff et al. 2016 JPSM

The role of PC specialists in training non-specialists on communication about dying and death?

Approaches to teaching

- Educational interventions vs. Teachable moments
  - Interventions
    - Most research has focused on low levels of impact:
      - Reaction of the learner
      - Knowledge of the learner
    - Less so on behaviors within a clinical environment, or on patient-level outcomes
    - Without routine assessment of quality of end of life care the changes due to training will not be seen

Downar, 2018, JPM

Teaching communication as specialists in PC

- A (wo)*man* with two hats
  - Expert communicator
  - Teacher of communication
- Failure to engage and debrief the learner may lead to misperceptions
  - Communication is **not** an innate talent

O'Neill and Back, 2012

Teaching communication as specialists in PC

- Create Learning Opportunities for Palliative Care Conversations
  - Identify *routine* encounters that can be life altering for the patient
  - Make the invisible, visible:
    - Will this information change my patient's day-to-day life?
    - Is my patient at risk of a serious complication or outcome?
    - Is my patient at a transition point in their illness?
      - If the answer to any of these questions is yes, this may be a learning opportunity to practice these skills
  - Avoid the mental hurdles: communication can be learnt one skill at a time
    - Focus on one goal for observation and feedback

Hurd and Curtis, 2016

Teaching communication as specialists in PC

- Give space and be open for referrals of a *different* nature
- Avoid communicating to learners that with generalist skills they should "always" be able to manage seemingly "basic" palliative care-related situations
- In relation-specific issues the problem may not be evident to the consultant

Condition specific
Severe refractory pain or other symptoms
Anticipated catastrophic end-of-life complications (e.g., massive arterial hemorrhage)
Requests to hasten death
Questions of medical futility

Relationship specific
Emotional closeness
Patient who has improbably survived similar situations
Difficulty with changing roles from "fixing" to "palliating" with a long-term patient
Patient with limited trust in the physician or the system in general

Carroll, 2018 JPM

Teaching communication as specialists in PC

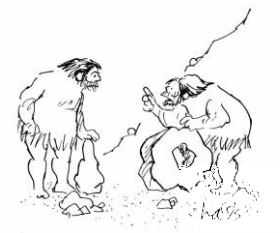
- Model reflective practices
  - Experiences in PC enable clinicians to develop as empathic and caring professionals
  - Encourage such encounters and facilitate self-reflection in others
  - Give permission for colleagues to feel vulnerable, so that they discuss their experiences to the degree they may need

Emmerich, 2018

Between teaching and collaborating

- Collaboration is seen as beneficial but can be challenging
  - Clarify roles to reduce power struggles
  - Include ward staff to their level of ability
- Education and skill-building influence the satisfaction for referring teams and benefit them
  - Skill-building occurs mainly through observation of the specialist palliative care team during a consultation
  - Deskilling can be a concern of older staff
    - Faculty development

Firn et al. 2016; Pall Med


"IT MAY NOT BE A PERFECT WHEEL, BUT IT'S
A STATE-OF-THE-ART WHEEL."