



**We can't always
cure, but
we can always care**

**Relate to and handle death and dying
with emotional competence**

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with materials from Liiga Kuksa

Referencing and acknowledging the iCARE-Haaland model

- *Please feel free to use and adapt the material in this presentation, and the model it is built on, by referring to the model, and the authors:*
- This presentation is adapted from «***We can't always cure but we can always care***», which is part of the learning materials in the iCARE-Haaland model.
- **To reference this content please use the following:** Haaland A, with Boga M, 2020. Communicating with awareness and emotional competence: introducing the iCARE-Haaland model for health professionals across cultures. With contributions from training teams, Vicki Marsh and Sassy Molyneux
- <https://connect.tghn.org/training/icare-haaland-model/>
- The authors' names should remain on the presentation, with a by line recognizing the person who (has adapted and) is presenting the presentation

This presentation is based on your own examples

- When facilitating similar presentation with nurses, many cry, as they share experiences of facing death
- Feedback from them shows open sharing was felt as difficult, and liberating, and very useful
- You are free to share what feels ok.
- The important things is – to show care and compassion to each other, and – to listen with the intention to understand, and support

Biomedicine, life and death

- *Birth is a miracle, death is a mystery, neither fits neatly with the biomedical model....*



Participant's wish for learning



- *«Dealing with emotions of parents who have lost their loved ones. This is because after losing a patient, we lack the right words to console and comfort this parent/relative, and they end up thinking we are inhuman and we have no feelings. As this is what most of them say.»*

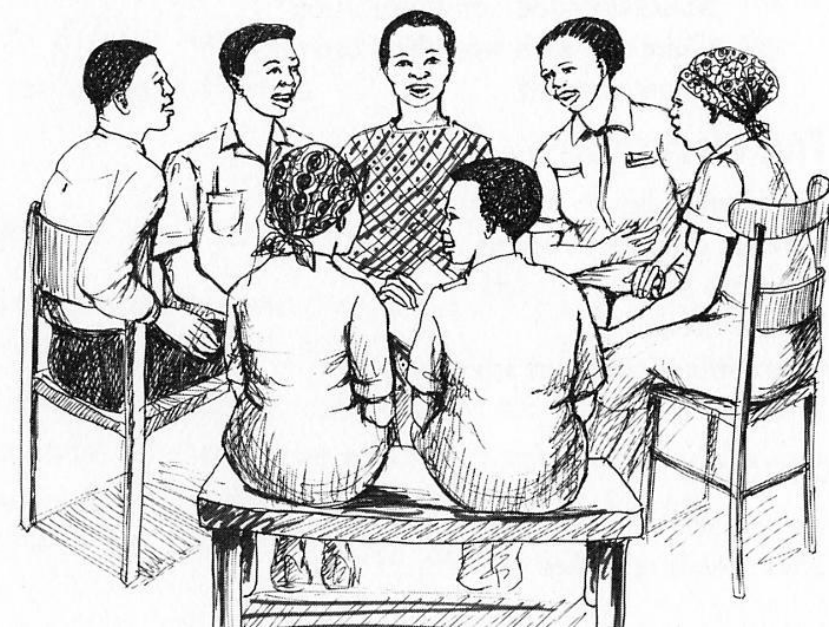
Objectives

- Acknowledge and strengthen awareness of –
 - providers' ***own fears and emotions towards*** death and dying;
 - Providers' own needs when faced with this;
 - Some reasons why providers find this theme difficult to handle
- To strengthen providers' ***awareness about and understanding of***
 - Patient fears associated with death and dying
 - The needs of a dying patient and the parent of a dying child
- Strengthen skills to handle death and dying respectfully, with kindness and emotional competence
- Share strategies on how to overcome the present challenges, using emotional competence

Resistance to talking about death?

Discuss in groups:

- Is there resistance to talking about death and dying in our culture? **Why?**
- ***Share examples*** of how you talk about death as medical professionals e.g when a child has just died
- *Write examples on flipchart.*



Participant's example

- *“A lady lost her husband in the ward from HIV related conditions. This lady found out about her HIV status while in the ward. She also didn't know her husband's status before, yet the husband was a defaulter since 2013 and had lost the previous wife for the same.”*
- *This young lady in her twenties was sobbing, asking what a hell that this man wanted to kill her as she remembered the big church wedding they had last year. She had not known any other man before. I had no words to comfort her, instead I found myself sobbing with her. Where was I to start?”*

Some reasons for the reluctance to talk

- **Cultural traditions:** Taboo to talk about death:
 - «Talking about death will hasten the process»
- **Medical tradition:** Death is a failure
- **Medical training at all levels:**
 - Focus on HOW to hold «difficult conversation», as technique
- **But lack of focus, in training and CME, on:**
 - Emotional competence – recognizing your own as well as patient's emotions, and stepping back, with awareness and empathy
 - Benefits to patient and HCP when you have honest connection with dying patient, and their relatives
 - Fear, vulnerability and other emotions of HCPs = taboo? Why?
 - The consequence for HCPs of not being taught to handle death and dying with EC – to them, and to patients and relatives

How do you relate to and deal with a patient who is dying?



- Please ***share experiences*** you have had, and discuss strategies you used to take care of the emotional needs of patients and/or parents
- Write strategies on flipchart

Respecting emotions creates trust

- *«When patients' emotions are respected, they develop trust and confidence both to the organization and health care providers.*
- *I nursed a very sick child, who later passed on, and the mother was very emotional. I sat down with her and explained from the start since admission the condition of the child. First she couldn't talk but as I continued, showing her respect and caring about her emotions she opened up and gave more stories about the challenges she is facing at home.*
- *I reassured her and she became very positive and thanked me so much for coming and respecting her, I was very elated for what I have done and I felt I am very important person”*

HP's patience to let relatives understand information

- *«A patient passed on in the ward, relatives needed to know what next so as to see their departed person is put in a good place. I took the relatives to a private room, gave them my pole* for the loss and gave them the information. They asked the same question three times. I didn't give up, I made sure they understood by telling them so. «Now we understand, nurse – thank you»*
- *«Pole» is a kiswahili word that means «I am sorry for you», and is used to express empathy.*

Research evidence:

Openness is helpful – Denial and hiding info = not helpful



- **Openness from health personnel is helpful.**

Hiding info does not meet the dying patient's needs

Beliefs that disclosing prognostic information may result in increased anxiety and depression or destroy hope have not been supported by research findings

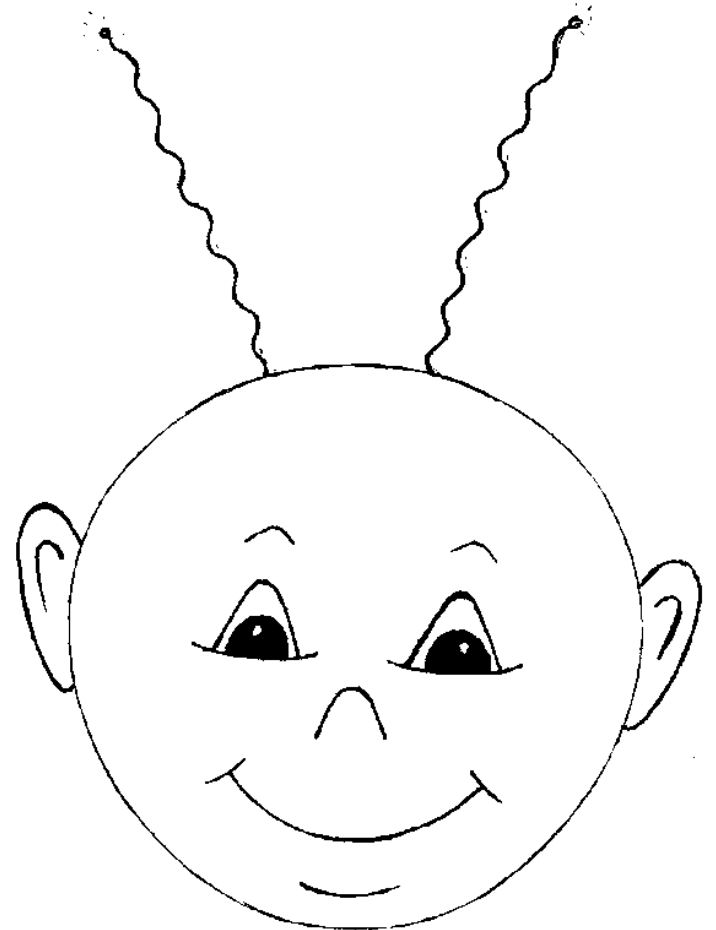
How do we cover up our fears?

- Do we have **fears** dealing with death and dying?
- What do we do to **cover up our fears**, when dealing with Death and Dying?
- How **effective** are our strategies?
- Are they **respectful**, towards ourselves?



Automatic reactions when we are fearful of death

- ***Common reactions:***
 - Withdraw
 - Be impersonal
 - Be cynical
 - Pretend we don't care
- ***Purpose (subconscious):***
- Protect our (vulnerable) feelings
- ***Alternative:***
- **Awareness;** presence. Handle with emotional competence



What are patients' fears and needs when they are dying?



- Please remember patients you have been nursing, who knew they were dying
- **Discuss:** What do you think the patients were afraid of?
- What could be their *needs*, when they are facing death?

The fear of dying: **Widespread, deep**

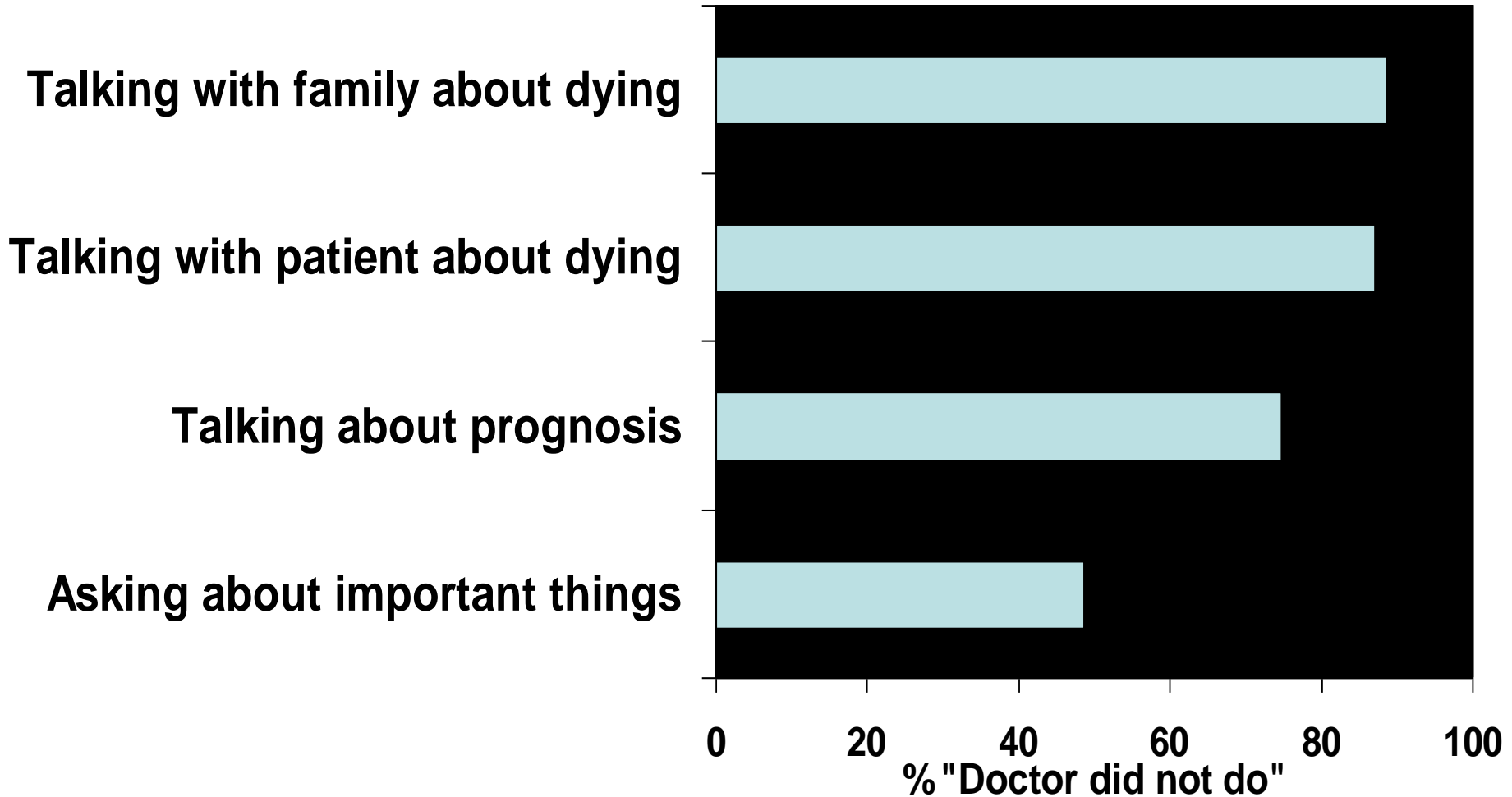
Seven common fears of dying are:

- ***Fear of the dying process:***
 - “What will it be like? Will it be painful?”
- ***Fear of loss of control:***
 - “Will I be dependent on others? Will I be unable to care for myself?”
- ***Fear of loss of loved ones:***
 - “How will they manage without me?”
- ***Fear of others’ reaction to them:***
 - “How will people cope with seeing me like this?”
- ***Fear of isolation:***
 - “Will people stop coming to see me?”
- ***Fear of the unknown:***
 - “What happens after you die?”
- ***Fear that life will have been meaningless***



Naming and recognizing the fear can reduce it.

Communication With Physicians: Severe COPD “*Doctor Did Not Discuss*”



Some possible reasons for patients not asking

- HCP using **medical jargon**; patient does not understand
- Patient **does not dare asking questions**
- Patient's **anxiety, depression, fear** («focus on own emotions» = not listening well)
- **Unclear** to HCP if and what patient wants to know
- **Unclear** cultural expectations
- **Avoidance** is «the easiest way out»



- ***Could it be that both are guided by fear?***

Study on cancer patients: Needs of dying patients



- Need for **support** after breaking bad news
- Need for doctors to seek common ground with patients as a *fellow human being*, and **attend to the emotional needs of the patient**
- Emphasize on the importance of **empathy and respect**
- Treated with a sense of humor and **politeness/kindness**
- Need to **respect individuality** rather than stereotyping
- Do things that are of **benefit to the patients**, not to the Doctor

«...I am nothing, but my illness»

- *“I’d like my doctor to scan me, to grope for my spirit as well as my prostate. Without such recognition, I am nothing but my illness”*



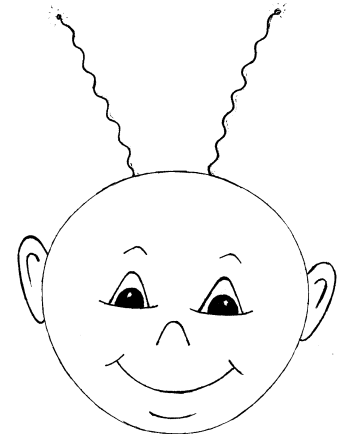
What do patients know, and want?

Studies show...

- **Patients do not know:** The majority of patients with terminal illness do not understand they will die. Many have unrealistic hopes
- **Want to know:** The majority of patients and caregivers want to know about their prognosis
- **Only few talk:** Only 8% of patients with thoughts and feelings about death take initiative to talk with their HCPs about death and dying

Denial: a natural protection

- Some patients do not want to take in the reality that they will (soon) die
- Behind denial is very often fear
- HCPs need to be sensitive and respect patients' fear
- Use EC: When HCP recognizes her own fear and takes a step back from this – s/he is also able to respond more appropriately to patients' fear and denial



“Good Death”: components

- **Pain and symptom management.**
 - Fear dying unattended and in distress
- **Clear decision-making.**
 - Empowered by participating in treatment decisions
- **Preparation for death.**
 - Want to know what to expect and plan
- **Completion.**
 - Faith, spiritual, life review, conflict resolution, time with family and friends, saying goodbye
- **Contributing to others.**
- **Affirmation of the whole person.**
 - Understanding current condition in the context of life, values, and preferences

*Dr Jason Ward
Consultant in Palliative Medicine
Mid Yorkshire NHS Trust
The Prince of Wales Hospice*

This was from research in 2003.

What now, almost 20 years later?

- The majority of doctors are still reluctant to talk about death and dying.
- Most of them have not learnt how
- Only 8% of patients with terminal diagnosis initiated talks with their HCP
- Patients receiving palliative treatment often have misunderstanding about their prognosis, the intentions of the treatment, and have unrealistic hopes of cure

Attitude that needs changing -

From -

- *«Death is a failure of medicine», thus «I don't want to talk about it.*
- *I don't know how, and I am afraid/feeling vulnerable.*
- *These feelings I cannot admit to or discuss with anybody»*

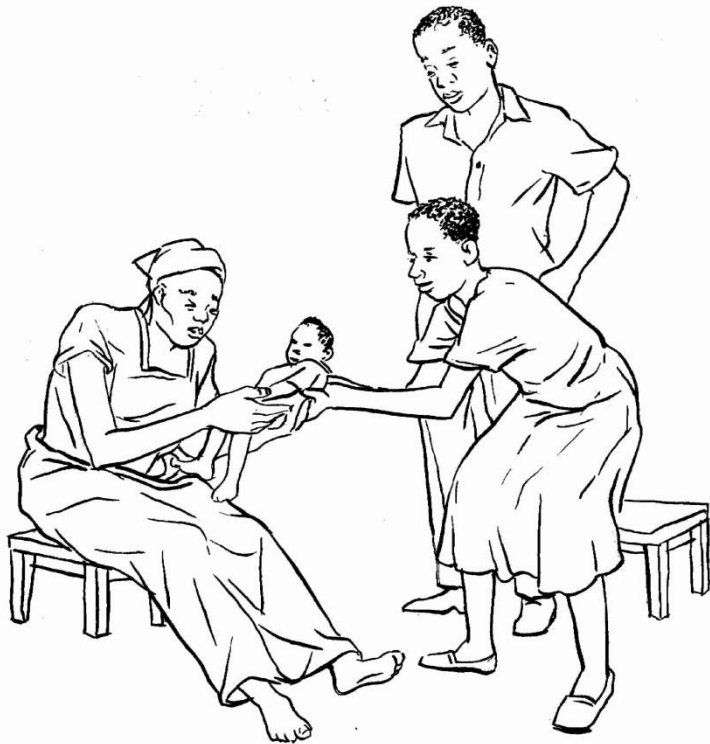


To –

- *«Death is natural, we need to face it*
- *Talking openly with a person facing death can increase the connection with him/her.*
- *This will help make the job more rewarding and meaningful»*



What influences how health providers deal with death and dying?



- Fears and anxieties
- Past experiences
- Culture
- Our attitudes
- Lack of skills to handle emotions

Taking care of providers' own needs

- How do you take care of your own emotions in this situation?
- Discuss how you can help each other
 - recognise,
 - acknowledge,
 - respect +
 - take care of feelings -
- when dealing with death and dying



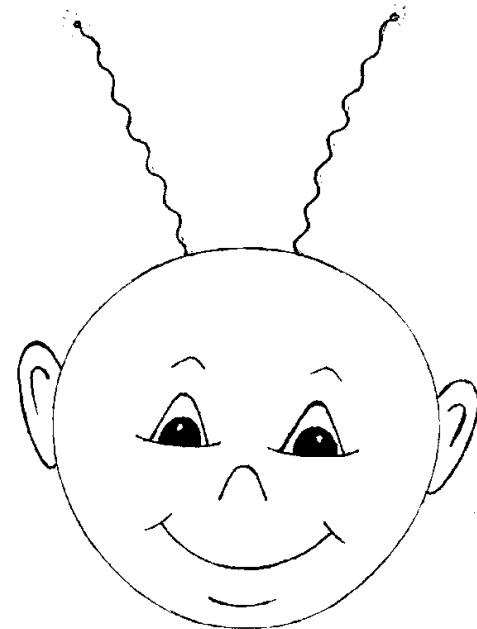
Crying with patients – with awareness

- Many HPs are afraid of crying with patients, or with relatives who lost a dear one
- Why do we fear crying?



Crying can have positive effect:

- Releases stress and tension
- Patient and relatives feel comforted
- Crying with awareness = healthy for HP, and patient



Core attitudes and skills when patients are dying

In Kilifi, providers say the following is helpful:

- **Awareness and presence**
 - Be there with the whole of you
 - Show empathy and compassion; build/confirm trust, get involved
 - and be able to step back from your own emotional reactions
 - Focus on the moment
- **Acceptance**
 - Put aside personal preferences
 - Don't be critical
 - Be tolerant, patient, flexible
 - Listen, with awareness
- **Take care of your own emotions**
 - When appropriate, get support for yourself



Communication with dying Patients: **Competencies needed by providers**



- Listen to patients
- Encourage questions from the patient
- Talk with patients in honest and straightforward way
- Give bad news in a sensitive way
- Willing to talk about dying
- Sensitive to when patients are ready to talk about death

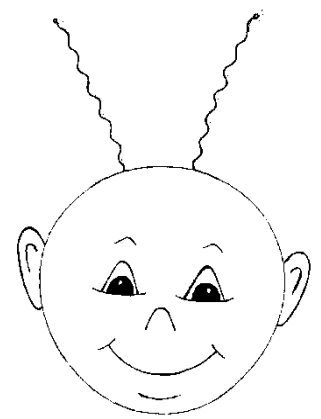
Participant's example

- *“I was working in casualty. One day we got a young man who came in unconscious with very high blood pressure. We did the necessary and stayed with the patient for almost 8hrs in casualty, because of the uncontrolled BPs.*
- *The wife with a small child beside her was very scared and from her words she was just seeing that we as the health providers looked worried, so all that worsened her feelings.*
- *I called her after the stabilization, sat her in a quiet room, let her cry it all out, had a conversation on the condition of the husband and outcomes, and how she perceived them. After 3 days she came looking for me in casualty and thanked me. Even though her husband had passed on she was glad she got to understand and it helped her”*

Experiences and reflections of providers in Kilifi

- Example that shows our lead trainer used the skills described when dealing with a dying patient and his relatives, and with herself.
- The example is long, and best read out from the module to the participants – rather than being shown on the slide
- Please use your own example, if possible

Summary



- **Communication about end-of-life care**
 - Often poor and *not meeting patients' needs*
 - Need to acknowledge personhood beyond the illness itself and recognize the emotional impact that accompanies illness
- **Depression and anxiety play an important role in this area – management of emotions = key**
- **Awareness of our own attitude, anxieties and fears – key in handling death and dying patients with respect**
- **Key competencies – Respect and Kindness:**
- **Communicating with emotional competence**
 - Recognizing emotions, step back. Listening with empathy, being authentic, honest and sensitive

Resources and references

- **Hack, T et al (2005) The communication goals and needs of cancer patients: a review. DOI: [10.1002/pon.949](https://doi.org/10.1002/pon.949)**
- Curtis, J.R et al (2004): Patient-physician communication about end-of-life care for patients with severe COPD. *European Respiratory Journal* 2004 24: 200-205; **DOI: 10.1183/09031936.04.00010104**
- Gunaratnam, Y. (2007). Intercultural palliative care: do we need cultural competence? *International Journal of palliative Nursing*, 13, 470-477.
- Warnock, et al., 2010 **Breaking bad news in inpatient clinical settings: role of the nurse**
- <https://doi.org/10.1111/j.1365-2648.2010.05325.x>
- **Worthington, D (2007) Communication Skills Training in a Hospice Volunteer Training Program.** <https://doi.org/10.1080/15524250802072021>
- Alghamdi, N et al (2021): Review Article: Use of Simulation to Improve Emotional Competence at End-of-Life Care for Healthcare Professionals and Students: A Scoping Review. <https://doi.org/10.1016/j.ecns.2021.03.005>
- ***Talking about dying 2021: How to begin honest conversations about what lies ahead .** Royal College of Physicians London. <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-2021-how-begin-honest-conversations-about-what-lies-ahead>
- ***Brown, S (2019): Why many doctors still find it difficult to talk about dying with patients.** *CMAJ*. 2019 Jan 7; 191(1): E22–E23. doi: [10.1503/cmaj.109-5691](https://doi.org/10.1503/cmaj.109-5691)
- ***REVIEW ARTICLE 2016: Palliative care in cancer: managing patients' expectations**
- doi: 10.1002/jmrs.188. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5167285/pdf/JMRS-63-242.pdf>

From the literature:*

Lack of communication and EC skills lead to emotional exhaustion

- “Healthcare professionals with insufficient training in emotional competence and communication skills at End Of Life experience substantially more stress and emotional exhaustion as they attempt to control their own emotions and those of others (Asai et al., 2007; De Paiva et al., 2017; Martins Pereira et al., 2011).
- The emotionally challenging contexts in which EOL care occurs require clinicians to deal with life-and-death decisions. Interventions that address the psychological aspects of care are critical for promoting emotional competence among healthcare professionals and students for EOL care. Emotional competence is the capacity to identify, decipher and act on your own and others’ emotions and it includes skills such as having the capacity for empathic engagement in other's emotional experiences and being aware of emotional communication (Ciarrochi & Scott, 2006; Saarni, 1999).
- ***From:** Alghamdi, N et al (2021): Review Article: Use of Simulation to Improve Emotional Competence at End-of-Life Care for Healthcare Professionals and Students: A Scoping Review. <https://doi.org/10.1016/j.ecns.2021.03.005>

From the literature:*

Emotional needs of patients need to be attended to

- “Optimal medical management includes discussions about disease status and the treatment plan, and the effectiveness of these discussions is frequently determined by assessing patient understanding, satisfaction, and well-being. The literature suggests that cancer patients continue to have unmet communication needs, and communication outcomes are enhanced when physicians attend to the emotional needs of patients.”
- *Hack, T et al (2005) The communication goals and needs of cancer patients: a review. DOI: [10.1002/pon.949](https://doi.org/10.1002/pon.949)

From the literature:*

Patients want to talk

- «Open conversations about prognosis, palliative care and end of life can often be welcomed by the patient or their family as a chance to gain more information about their prognosis and treatment options, and to exercise some choice and preference. Research by [Macmillan Cancer Support](#) showed that only 8% of people with cancer who said they had thoughts and feelings about death had shared them with their healthcare team. Of those who had, only 19% of the conversations were initiated by the healthcare professional.
- (...) Our research in 2018 found multiple barriers to having open conversations about death. A widespread culture of avoiding discussing death and expecting modern medicine to cure all ailments is one. This may be the case, but [77% of the public in England stated that they would want to know if they had less than a year to live](#). As tough as initiating these kinds of conversations can be, they can help to manage emotions and improve quality of life. Not every patient will want to talk about death, and those that do not want to, should have their wishes respected, but every patient should be given the opportunity to have the discussion.”
- ***Talking about dying 2021: How to begin honest conversations about what lies ahead** . Royal College of Physicians London
- <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-2021-how-begin-honest-conversations-about-what-lies-ahead>

From the literature:*

«Talking about death won't kill you»

- “The report (*ref slide above*) cites three barriers identified by doctors. Some struggle with the limitations of medicine, perceiving death as failure, while others feel ill-equipped to initiate the conversation. The final barrier was of a more practical nature: confusion over which of the patient’s caregivers should take the lead in opening a dialogue.
- But Kathy Kortez-Miller says talking about death and dying should be a two-way street. “As recipients of care, we also need to build up our own abilities on the topic and let our health care providers know that we are willing to have that conversation,” she says. The palliative care division lead at Lakehead University’s Centre for Education and Research on Aging and Health, she wrote *Talking About Death Won’t Kill You: The Essential Guide to End-of-Life Conversations* after realizing how difficult it was to discuss her own fears with her surgeon after a cancer diagnosis a decade ago.
- As for health care professionals, they also need to learn how to take the initiative when end-of-life conversations are needed. “If physicians can grow their capacity to have these conversations, they will increase their feeling of connection with some of the people they’re serving. It will ultimately help their jobs be more rewarding and meaningful for them. (cont)

(cont)

- That's a view echoed by Dr. Leonie Herx, president of the Canadian Society of Palliative Care Physicians. She notes that medicine is realizing the importance of teaching communication skills and normalizing “serious illness conversations” with patients. Like Kortés-Miller, she advocates for a cultural shift that encompasses both health care professionals and society in general. “Yes, modern medicine can do amazing things, but we are all human beings who live and die,” she explains. “We need to normalize dying and death as part of life. We need to use the D words.”
- Herx says discussing the possibility of deterioration and death should be part of a standardized approach to providing care and options for treatment once a patient is diagnosed with a life-threatening illness. Having that talk sooner rather than later also gives the individual and their family time to discuss the “what ifs” before they occur. “These conversations can happen at the same time as maintaining hope for cure or control of disease,” says Herx. “It can be a normal part of helping a patient and family understand and prepare for all of the possibilities.”
- (....) It all comes down to making people comfortable with the idea that death and dying are normal, natural parts of life. Even physicians must face the uncomfortable truth that not every condition is curable. “I’ve seen many physicians cling to very unrealistic ideas long after any chance to see those ideas work,” says MacDonald. “Why? Because they don’t know how to deal with the alternative.”
- ***Brown, S (2019): Why many doctors still find it difficult to talk about dying with patients.** [CMAJ](#). 2019 Jan 7; 191(1): E22–E23. doi: [10.1503/cmaj.109-5691](https://doi.org/10.1503/cmaj.109-5691)

Many misunderstandings – conscious communication needed

- “Advanced cancer patients commonly have misunderstandings about the intentions of treatment and their overall prognosis. Several studies have shown that large numbers of patients receiving palliative radiation or chemotherapy hold unrealistic hopes of their cancer being cured by such therapies, which can affect their ability to make well-informed decisions about treatment options. This review aimed to explore this discrepancy between patients’ and physicians’ expectations by investigating three primary issues: (1) the factors associated with patients developing unrealistic expectations; (2) the implications of having unrealistic hopes and the effects of raising patients’ awareness about prognosis; and (3) patients’ and caregivers’ perspective on disclosure and their preferences for communication styles
- (...) The discrepancy between patients’ and doctors’ expectations was associated with many factors including doctors’ reluctance to disclose terminal prognoses and patients’ ability to understand or accept such information. The majority of patients and caregivers expressed a desire for detailed prognostic information; however, varied responses have been reported on the preferred style of conveying such information. Communication styles have profound effects on patients’ experience and treatment choices. Patients’ views on disclosure are influenced by many cultural, psychological and illness-related factors, therefore individuals’ needs must be considered when conveying prognostic information”
- *REVIEW ARTICLE 2016: Palliative care in cancer: managing patients’ expectations
- doi: 10.1002/jmrs.188. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5167285/pdf/JMRS-63-242.pdf>

Recommendations from literature

- Normalize dying and death as part of life
- Teaching communication skills on how to approach patients and relatives