

Module 7 (2e)

We can't always Cure, but we can always Care: Managing death and dying with emotional competence

By Ane Haaland, with Mwanamvua Boga

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Background for trainer

Many providers identify death and dying as a most important topic to learn more about, and one which is not taught well in most pre-service or in-service education. When asking our trainers what they had learnt about handling death and dying during pre-service training, one of them said: *"We learnt to wrap the bodies"*. Others had similar experiences.

Skills to recognize and deal with the many strong emotions connected to the process and event of dying, for the patient, the family and the provider, need to be learnt through training and experience. Being able to face the fear and vulnerability on all sides during this process requires awareness and emotional competence, and an ability and courage to be present, to identify and meet the real needs and provide patient centred care, as well as showing empathy and kindness to the relatives. Participants are now ready for this challenge.



There are many taboos connected to talking about death and dying, based on a lot of (natural) fear from patients, relatives and providers – which again has many different reasons.

For patients and their relatives, the fear and pain are very difficult to deal with. For some, acknowledging or talking about the impending death is believed in some cultures to be hastening its arrival, and many therefore avoid it. This can be connected to a belief in witchcraft, or other cultural beliefs. For others, they simply do not know what to say or do. Handling fear and vulnerability is difficult for all – dealing well with strong emotions is a skill few people learn. Dying patients' needs are often simple (at least on the surface) - they need empathy, compassion, comfort and care. They may also need and want information, and an invitation to ask questions they are concerned about, but do not dare to ask. They need this care from a provider they trust, preferably a provider with whom they have a relationship throughout the illness, someone who respects them and sees them as a person. Someone who shows she cares, as a human being, and as a professional. Someone who is not scared of the patient's fear, and who can manage her own emotions when facing a dying patient and his/her relatives.

In medicine, death is often looked at as "failure" of the medical professionals to do their job of "solving the problem" to heal the patient, and there is reluctance to talk about it as the natural outcome it is, eventually, for all of us. The consequence is often that death is "covered up" by using internal jargon ("Bed 2 packed"; "He's gone"; "He has R.I.P."; "That patient – Salama, salama", "She collapsed", "He is discharged to heaven", "Death is promotion to glory", etc) to create a distance to

the event. The fear is sometimes covered up by providers cracking jokes after a patient has just died, even laughing, or pretending to be busy – which is of course experienced as extremely disrespectful and painful by e.g. a parent who has just lost a child. Many try to behave as if nothing happened, or simply ignore it, and get busy with other activities. This is usually a cover-up for “*I don’t know what to do, or say*”.

Providers who distance themselves from the event and the emotions surrounding it may not be able to offer dying patients and their relatives the empathy and support they need in this crucial time. They may also not be able to deal constructively with their own emotions related to death, and to the patients they are losing after maybe having cared for them over time. This can lead to inadequate care for the patients and their relatives/families, and to a potential build-up of unhandled emotions for the provider – which can again contribute to fueling conflicts, stress and/or burnout. When providers avoid recognizing and handling their own emotions in challenging and stressful situations over time, it can also potentially contribute to stress-related medical conditions e.g hypertension or peptic ulcers.

When providers have not learnt special strategies to handle dying patients, the most common behavior may be to react automatically – they distance themselves to protect their own emotions (*mainly fear and vulnerability, and sadness and perhaps guilt connected with relating to the dying patient*), because they do not have a better or more conscious choice.

However, when participants have learnt awareness and emotional competence – to recognize their own and the other persons’ emotions and respond to these consciously and with respect – they can stop the automatic reactions. They can make choices about how to relate to patients and their relatives, when facing the last stages of their lives. The task of meeting dying patients’ needs can then become more feasible.

The purpose of this module is to strengthen providers’ awareness of especially the emotional aspects of death and dying for their patients and for themselves, and to strengthen strategies to deal well with these – using the Patient Centred Care principles and emotional competence skills as a basis. Participants sharing experiences and strategies are very important when working with this sensitive topic, and – to give room and space for thoughtful and respectful reflections in the groups as well as in plenary. Trainer’s role should be to affirm and emphasize good examples that are brought out from the groups, and encourage participants’ learning from each other. The point should be that there is no “right and wrong” strategy – there are different ways of coping with these situations, and providers need to find their own ways that work well for them, and for their patients. Key strategies to emphasize will often be – recognizing and acknowledging fear and vulnerability, step back from automatic emotional reactions, being present with the patient, showing empathy and respect, giving space for questions and reflections, and allowing for everyone’s grief, including that of the caregiver.

This module may raise strong reactions among many participants. It is common for people in the caring professions to “bottle up” their own feelings about relating to patients’ dying, and to their relatives. In all the courses we have conducted, participants have been crying their own tears, finally being allowed to give space to their own emotional reactions to the tough situations they have dealt with. Many also cry for their own friends and family members they have lost, and for whom they may not have had the “peace”, or given themselves permission – to grieve and cry. It is important that the trainer is prepared for this, is comfortable with people crying in the groups, and says so in her/his introduction to presenting this module. The trainer should make it gently clear that crying is a most natural reaction to death, and encourage participants to also relate to it as natural – and as a painful, but healing reaction, including for men, who may need extra help to know that crying is not “unmanly” or a sign of weakness.

The trainer should also encourage participants to be sensitive, gentle and respectful to each other throughout the session, be empathetic and support each other – rather than e.g. telling colleagues to stop crying. The approach to promote is to be caring professionals who can relate to and reflect on their own as well as their colleagues' painful experiences in an honest, compassionate way. The trainer has an important task to role-model such a professional response. To be capable of doing this, the trainers must also have been allowed to experience their own grief for past losses, before this session. A box of tissues at the tables will usually be a good idea.

Participants in our courses have commented that being able to relate naturally, openly and respectfully to these strong emotions with their colleagues during this module has enabled them to relate to patients facing death, and their relatives, in a better way after the course. They have appreciated the opportunity to deal with difficult grief in a supportive environment, where a careful balance between learning skills and being able to deal with their own emotions, has been the aim.

A main skill to practice is **being present**, and being willing and able to be there for the patient and the relatives as a caring human being – AND as a professional. It is the skill to relate to people being vulnerable and in pain which is the most essential one to learn. To be able to do this – the provider must acknowledge, accept and be able to manage her own vulnerability – and handle this as a precious emotion that can help connect you with another person.

From the iCARE-Haaland model, part A, page 50:

Vulnerability: A source of human connectedness, and empathy

The ability to practice emotional competence (and EI) is to a large extent dependent on skills to recognize, acknowledge, appreciate and manage vulnerability. Vulnerability may be seen as an essential aspect of being human, and the very quality that enables a health professional to establish a connection with a patient, and enables the patient to speak about her deep concerns and fears. A young doctor participating in the training in Wales shared the following reflection of discovering the positive effects of applying emotional competence:

“Recently I was working in a pre-op clinic for patients who were due to undergo cancer surgery within the next few weeks (...) assessing their fitness for anaesthesia/make an anaesthetic plan - a rather routine process from my point of view.

(As) I introduced myself and my role to the patient and explained what operation they were due to have and why, (...) I recognised that this is where I feel vulnerable.....the patient is feeling emotional and faced with a lot of uncertainty..... normally my defences would kick in and I would shy away from the subject and press on with the consultation.

I recognised it was an emotional time for the patient and I decide to verbalise this - saying that this must be an extremely stressful time for the patient and that they must have a lot going on.....tapping in to past experiences from my past/family/friends to empathise with the patients situation. The patient opened up to me and I listened to her....giving her time to talk and reassuring her where I could. I felt like I was able to build a connection where in the past I would have avoided it.”

The connection to empathy: The American sociologist Brene Brown says that vulnerability is “...the birthplace of innovation, creativity, trust and empathy”¹, and shows how there can be no learning without vulnerability. Her extensive scientific research into vulnerability and shame has resulted in an understanding of the role and importance of vulnerability in relationships which is starting to break down the apparent taboo against speaking about the concept.

¹ Brené Brown | Daring Classrooms | SXSWedu 2017

The trainer can use her/himself as a role model – making participants aware that a main skill in facilitating this module is to be present, and be respectful and appreciative of strong emotions, experiences and issues that are brought up by participants, and relate to and handle these with empathy and kindness. At the same time, the trainer has to be aware of the “other part of the professional agenda” – the skills she/he has to teach.

Safe space to debrief: Another skill to be aware of and emphasize with is the importance of providing safe space, when people feel vulnerable. For the provider who has just experienced a patient dying and have dealt respectfully and compassionately with the relatives, she herself may need a “safe” person to debrief with. When the provider is feeling vulnerable, she needs empathy and compassion as well, to be able to process her experience in a good and gentle way. In many places, the team of providers being involved with a death will meet with a psychologist or a facilitator, to share experiences and emotions, debrief the event, and be ready to move on. Where these are not available – awareness, kindness and empathy from colleague(s) go a long way.

From the iCARE-Haaland model part A, pp 51-52:

Research into vulnerability as a potential resource

There exists some, though scarce, research on professionals’ relationship to vulnerability, and its connection to ethics. Conclusions from these may be summarized as follows:

Recognising and managing vulnerability can be taught as a strength, a resource helping health providers to achieve important goals in their work:

- ***It improves the capacity to connect with and relate to both oneself and to other people***
- ***It provides a basis for experiencing empathy, including for being kind to oneself;***
- ***It helps one learn how to nurture, including oneself;***
- ***Thus, it helps one find and maintain balance in life.***

Some brief examples from the literature:

In her investigation of how doctors use vulnerability, and how it can affect patients, **Kirsti Malterud**, a Norwegian researcher who is also a GP, concluded:

“The doctor is expected to be detached and omnipotent, yet compassionate and empathetic. Attention is usually drawn to the negative aspects of doctors’ vulnerability and emotionality related to burnout or misconduct. Focusing on the potential benefits of vulnerability in the doctor, we find that it may bring strength, but must be used with caution.”²

Gjengedal³ investigated the link for health professionals between empathy and vulnerability: She found that a strategy to help them understand the patients or families from **their** own perspective “...seems to make vulnerability bearable or even transform it into strength. Being sensitive to the vulnerability of the other may be a key to acting ethically”. When the professional attempted to help from **her** own personal perspective, her attention remained on herself, and this could impair the ability to help.

The authors conclude:

»However, in order to recognize vulnerability as strength, one needs help to face one’s vulnerability in the first place. Then, a gradual growth process leading to flourishing might take place⁴.»

² Malterud, K (2009): When doctors experience their vulnerability as beneficial for the patients. A focus-group study from general practice. Scandinavian Journal of Primary Health Care, 2009; 27: 85_90

³ Gjengedal, E & al (2013): Vulnerability in health care – reflections on encounters in every day practice. <https://doi.org/10.1111/j.1466-769X.2012.00558.x>

⁴ Gjengedal, E & al (Ibid)

“Crying with awareness”

Participants who have managed to practice being present with the dying patient and/or their relatives experience that although this is a very difficult thing to do, it also helps them deal with the situation better themselves – in addition to helping the patient and her family. One of our trainers who recently lost her own daughter, comforted a mother who lost her little girl to the same disease, and sat down and cried with her. The mother was very thankful for the support and compassion she experienced, and the trainer felt it helped her with her pain, too – by being able to share some “honest tears together” – while still being aware of and fulfilling her role as a professional and empathetic health provider. We call this “crying with awareness”, allowing tears of compassion and sadness to come out in the face of death, when it is a natural emotional response. Tears are usually experienced as a very honest and empathetic response, and patients and relatives usually feel they can trust a person who shares tears with them. Tears can clear the air and the heart, and can give vulnerability a “face”. It is often followed by being relieved.

NB: It should be noted that there is a large difference between “using others to heal your own pain”, which would NOT be experienced as caring (because the focus will be on yourself), and – responding naturally to a situation like the one described above when it happens – which MAY BE experienced as caring, for both persons. The key is to be aware, and to keep the professional relationship and the needs of the relative who has lost a dear one, at the center – while responding also as a human being.

Encourage sharing of real examples: If you know of any of the providers who has dealt well with a situation relating to death and dying recently, and is willing and able to share and/or demonstrate what she/he did, this is often a very good way to introduce the exercise of sharing experiences and strategies. The trainers can also share such an example* if none is available from the participants. The challenge for the trainer is to get the participants to share real experiences, rather than talking about what “should be done”, or what others have done. When one honest example is shared in plenary, it gives the others “permission” to also talk about “the real things” that happened, how they really felt, and what they did – including when they felt they did not do what they would have liked to do, maybe because of fear, or not knowing how to do it.

***NB it is NOT recommended that the main trainer shares his/her own experience** while facilitating the session, unless it is from an experience several years ago which has been well “processed” by the trainer, and he/she has enough distance to it (*and even then – rather not*). The emotions which are involved in relating to one’s own experience of being close to people who are dying are very strong, and it is extremely difficult to do this well, and at the same time facilitate this very challenging module and teach people the skills they need. A main problem will be to set functional boundaries and manage time: Participants may want to talk extensively about their experiences (e.g. sharing in the big group/the whole class) once given an opportunity they may have been longing for but not had, and – many others may want to do the same. It takes a focused presence of the facilitator to be able to stop people gently when needed, and to set a boundary to not let all other stories be told (when running out of time) – and ask participants to continue to share with each other, after class and after the course. Doing this is a challenge, and almost impossible to do when one’s own experiences and vulnerability is mixed into the situation.

Keep the “tone” personal, but set boundaries

It is essential to keep this session personal, empathetic and at the same time professional – and not let emotions be shared without also being able to set boundaries: The trainer setting healthy limits with participants will also role-model this behavior for the providers when they go back to work to implement these skills. They should teach how to find ways to assess when, with whom and to what extent providers can relate safely to this difficult topic, as a contrast to the automatic emotional behavior of “bursting out” or “bottling up” natural feelings around death and dying. The automatic

behaviors usually happen because of fear, and because participants have not learnt the skills to recognize and handle fear in a constructive way – using emotional competence.

From the iCARE-Haaland model part A, pp 52-53

Vulnerability: Approach, but with educated caution

As described above, these skills are much needed in the medical profession, enabling providers to identify more accurately with their patients, which in turn enhances the possibility for understanding them. When the health professional is able and willing to share – carefully, appropriately and with awareness – from her own life experiences and the vulnerability they evoked – the health professional becomes *a person* to the patient, potentially deepening their mutual empathy. This can influence on the quality of clinical practice. However, training is required to utilize this resource responsibly.

Boundaries needed: The awareness necessary for determining how, when, with whom and to what extent to express vulnerability – or not to do so – demands that the health professional develop well-functioning boundaries. She must ensure that there is a balance between what she takes in and what she gives out. For example, she needs to protect herself, having empathy also for herself and her own vulnerabilities and needs, as well as for those of the patient. If not, she may become emotionally exhausted and prone to burnout. To become skilled at using empathy and vulnerability with awareness, providers need to reflect personally and interactively with others about their own difficult emotional events, sensitive situations and general sensitivities.

Acknowledging imperfection: Health professionals may not be well known for acknowledging mistakes and apologizing to their patients or colleagues. To be able to determine when and how to do so, honorably, appropriately and sincerely, the HP needs to acknowledge her own vulnerability, including in the context of medical legal requirements.

There are 6 sections in this module. An overview:

1. **Introducing the topic**, the challenges of dealing with this topic in the biomedical model where death does not fit, and participant’s strong need to learn about how to handle emotions well in this situation. Setting objectives (slides 1-6)
2. Exploring **cultural reasons for reluctance** to talk about death; sharing **experiences and strategies** for how we talk about death, and how we deal with **patients’ and family’s’ emotional needs** (slides 7-13)
3. **Exploring fears around death:** How and why **providers’ own fears are covered up, automatic reactions to fear, exploring patients’ fears and needs**, and contrasting with research showing how doctors (don’t) deal with dying patients’ fears. Re-visiting the literature – seeing what has changed in 20 years; Identifying attitudes that need changing (slides 14-26)
4. Focus on **providers’ own reactions, reasons** for these, and how providers can identify and take care of their own needs to be able to communicate well with dying patients and their relatives – using emotional competence (slides 27 - 30)
5. **Competence and skills needed** from providers, and summary (slides 31-34)
6. **From the research literature:** See slides in the pptx presentation (slides 35 – 42)

Further background about purpose and contents of the sections:

1. Introduction: learning about emotions, and the biomedical model

The relevance can be set by asking the participants how dealing well with death and dying is relevant to us as health providers. Getting some reflections, you can **acknowledge** that the task is difficult,

especially related to recognizing and managing the emotions. The aim of this module is to learn how to recognize and respond appropriately to patients' emotions when they are faced with their own impending death. Participants learn how to recognize, understand and respond well to their own emotions, and to support colleagues who are experiencing emotions when sharing examples and strategies. It is important to "give participants permission to cry" – by acknowledging vulnerability and crying as a natural response to this topic. The trainer should make it clear that shedding tears is natural and very acceptable during this module, that many participants commonly do so, including men, who may need extra help to know that crying is not "unmanly" or a sign of weakness: crying is commonly experienced as helping to heal the pain related to experiences with death and dying. When crying – you show your vulnerability, which inspires positive feelings and a wish to help. Participants can use the opportunity to practice showing each other empathy, compassion, care and comfort.

Acknowledge that learning about this topic is a challenge in medicine, because somehow, it does not "fit" in the biomedical model: Birth is a miracle, because we can explain what happens right from conception to delivery, but can we really explain what happens in death? Read out the objectives.

2. Exploring culture, experiences and strategies for dealing with death

There are many cultural reasons for the reluctance to talk openly and honestly about death – and many of these are not "known", not talked about explicitly or openly. They are "just there", influencing behavior quietly through "unwritten rules". Exploring these reasons and making them explicit provides a good basis for understanding some of the personal and professional strategies participants use in their work. Linking cultural reasons to their own practice, and reflecting on these, opens and debates participants' "permission" to question the cultural rules, and maybe make different choices that support their work and their emotions better - by practicing emotional competence.

Much good learning takes place when participants share strategies that they have used and discuss how they worked/if they met the needs of the patients, and themselves. Such sharing and reflection is a very important part of this module – which is less about learning "the perfect strategy", and more about acknowledging patients emotions, and providers' own emotions, when dealing with death and dying. Through sharing such deep experiences and hearing how colleagues have also despaired and struggled in these situations, participants become more able to tackle their own emotions with awareness and kindness the next time they are faced with the end of life.

3. Exploring patients' and providers' vulnerability, fears and needs

Recognizing and acknowledging fear as the main emotion, and understanding the common fears of dying people, can make providers more able to meet these needs. This discussion can be linked to the initial one about culture – where in many cultures, talking about fears and acknowledging vulnerability is not encouraged, and barely accepted. So – providers who do want to change the way of relating to patients' and relatives' needs must be prepared to challenge culture, to some extent. The discussions among participants on these issues will likely bring out the fact that commonly used (automatic) reactions and strategies – to cover up their own emotions, distance themselves and not get involved with really comforting patients and relatives facing death – are not meeting the needs of the patients and the relatives. These reactions are also not meeting the real needs of the providers themselves. Neither party is able to relate well to the strong emotions present and may thus not be able to process the event respectfully. Sharing and reflecting on such experiences and also on some experiences where patients and relatives' needs HAVE been met, is the purpose here. Through the explorations and reflections, the key direction and aim to keep in mind is – promoting awareness, and the ability to recognize emotions, step back, and act with respect and compassion. Or in short form – communicating with emotional competence.

As the sharing of experiences will be bringing out many emotions, it is also important to “shift gear” and provide some knowledge from studies conducted on the topic, studies that confirm that what this course is doing, is linked to/responding to research results. The slide showing how limited doctors’ responses are to meeting the dying patients’ needs, shows clearly that the problem of relating to vulnerability is something providers in most countries struggle with.

We reviewed some of the literature and saw that nothing much has changed in this area – there is still a relatively unacknowledged need for health personnel to learn to manage their own as well as the patients’ and relatives’ emotions related to the dying process, in many places. We have suggested an important attitude that needs changing.

4. Providers’ own reactions; reasons for these; taking care of own needs

So far, the focus in the module has been to explore the needs of patients and relatives, reasons for these, and strategies providers use. This section should focus further on what is behind providers’ behavior when they relate to death and dying, and on how to meet providers’ needs in practical ways, to enable them to take care of their own (emotional) needs. Cultural “rules” of not showing emotions, especially crying, can be explored and challenged. Crying with awareness can be discussed as a natural and healthy response to death – when provider is able to handle it consciously and respectfully – and not be lost in the emotion. Developing skills to communicate with emotional competence is the aim.

5. Competence and skills needed from providers, and summary

The competence needed from providers to relate with awareness and compassion to patients and their relatives facing death, are the ones being taught in this training course: Communicating with emotional competence. Information from research is used to highlight this point. The core attitudes and skills needed are summed up, with an experience from a provider in Kilifi to bring the points together.

6. Resources from the literature

A number of articles and reports have been reviewed, and are included, with links.

Time needed: 3 ½ hours, with a break after 1 ½ hours and 2 ½ hours.

Time management: There are 5 exercises in this module, each requiring about 15 minutes. Trainer should aim to complete slide 18 by the end of the first session, even if this session goes a little over time (but – not more than 20 minutes over the time). A natural break after dealing with patients’ death and relating to relatives is needed, to allow participants to shift the focus to taking care of their own needs in the last part of the module. A review and reflection on skills needed will bring the learning together, and we will end the session with a focus of (slightly) less emotional aspects. If it seems clear that there is need to use more time, ask participants’ agreement to do so. WE have done this in Kilifi when participants had a lot of important experiences to share and process, and it seemed wrong to simply “follow the programme”.

Handouts: Presentation (6 slides per page, double-sided = 6 pages)

Materials needed: Flipchart, marker pens, tape to put up flipcharts on the wall.

Facilitator/co-facilitator roles: This presentation is best done by an *experienced trainer*, by her/himself. Other trainers function as assistants, rather than “co-facilitators” (*see definition*).

Some personal stories from trainers and caregiver

Our trainers care for dying patients and witness these patients dying regularly, and speak with the patients' relatives – to comfort, empathize and inform. This module is aimed at building skills to enable the health providers to do this very important work in a better way – a way that meets the needs of the dying patients, relatives, and – of the health providers themselves.

Below are two examples of how our trainers have managed challenging situations and share insights from these.

We also include an example from the author of the iCARE-Haaland training model, who lost her husband to cancer. She shares how health providers supported them (or not) throughout the process – for over three years.

Crying with awareness

A senior trainer contributed her example of empathic crying

“Recently, I was attending to a child with severe anemia. Suddenly the child stopped breathing, and we lost the child. I knew what the mother was going through, as I have been there myself – losing a child. I cried with her, with awareness. I showed empathy, and we connected over her child’s death. I had not seen her with relatives, and asked her whom we can call, if she would want to speak to the dad. She said - no – you please tell him. Then, I took her to a private place where she could grieve in peace, and comforted her. I was there as a professional, for her and with her, and – I was also there as a human being, with my compassion, being present with her. She was ok after some time, and so was I.”

The trainer said further that for her, she needed to sometimes cry about her own child and talk about her to friends, at home. Friends often told her not to cry, but she asked them to let her cry, and let her talk – this was her way of coping with the grief. She was aware of her needs to deal with her grief by crying, even when the friends were uncomfortable with her fear, and her tears.

Breaking some cultural barriers and habits is needed!

Hiza Dayo, Clinical officer, Senior trainer

Letting the parents witness their son dying

A mother brought in her 10year old son to the ward with a 2 day history of headache. She gave the boy paracetamol for the pain, waiting to take him to hospital the next day. In the morning the boy woke up feeling much better but the mother insisted that they go to hospital to have him checked.

The mother first left to go fetch water before they could leave for the hospital, leaving the boy playing with his peers in the compound. Just before she arrived at the well, she was summoned back - her child had fainted and was convulsing. She came back home and found her boy unconscious. With the help of neighbors they came to Kilifi hospital straight away. On arrival in the ward the boy was in bad shape and I could foresee that he may not make it. The mother was very anxious, I recognized her anxiety and straight away sat with her, found out the history of the illness, I empathized with her, I imagined how I would have felt if this child was my own. The boy was the same age as my daughter, and that motherly heart just engulfed me.

I appreciated her efforts to bring the child to hospital, I was honest with her that her child is very sick and we are worried about his condition but we will do our best. I explained every step we took

in the care of the child. I gave her a seat to be close to the child so that she can see each and everything being done. The child's condition deteriorated minute by minute and I let her know all what was happening. I asked her if the father could come over. She called the husband and let him know of the child's condition.

The father did not take long to arrive. When the father saw his boy in the state he was (wires all over, oxygen, tubes e.t.c) it was too much for him, I saw the anguish in him. He went on saying "my boy my boy, is this my boy, I left him in the morning playing with his peers, what happened?" I pulled him aside together with the wife; I introduced myself to him, empathized with him. I asked more about their family, and learnt that this is the only boy they had, they lost another boy aged 20 three years ago, it was just too much for them to comprehend. I felt their emotions infecting me, but I was aware and I had to maintain my own sanity.

Within two hours the boy went into a cardiac arrest, and all the clinical team was around the bed resuscitating the child. I let the parent be present, I explained all what was being done to the child, I was by their side present with them until the child died. I let them know that we are very sorry your child has died. To my surprise the parents did not overreact as I anticipated, they acknowledged the loss, stepped out of the ward for a while, then the mother came back and helped us prepare the body. She asked us to let her close her child eyes and mouth and we let her do so.

It was too much for me after boy passed away, I stepped out to the nurses' plaza, talked with a colleague about the case, had some tea and felt better. But to date I still remember this boy's death.

Insights: This was a tough death to the parents and the clinical team because we did not establish what caused the death. All investigations done were normal.

The skills I used to handle the situation:

- Being present, empathy, being honest and sensitive with the parents.
- Allowing them space to see all what was being done to their child
- Giving them room to ask questions
- Step by step explanation of the care given to the child.
- Acknowledging and showing respect for their emotions
- Allowing the mother to participate in preparing the body.

Mwanamvua Boga, nurse manager, lead trainer, Kilifi

A personal note: My husband is dying

In 2016, my husband Ueli died of aggressive brain cancer, after just over three years living with this death sentence. He died at home, and I held his hand as he passed over to the unknown side.

I would like to share some experiences of what we lived through during those three years, relating to health professionals. I reflect on what was helpful, what was hurtful, how it affected us, and how we coped. I am not claiming these are “representative” in any way, but several friends and colleagues have echoed such reflections.

“You will not become an old man”, said the doctor with a smile, speaking to us at the hospital. Ueli had arrived home from work in Nepal the day before. He was clearly ill, and was taken to hospital in a helicopter. Diagnosis: Glioblastoma, stadium 3 and 4. Together we met the doctor, who was – smiling, friendly and – distant. His delivery of the bad news without a hint of empathy or care was shocking, as he gave us the information that would change our lives, forever: You will die, soon. Average time left to live, at your age: One year. He gave a lot more information, which we did not hear (*and I learnt later that this is hospital guidelines – give all the information as you tell the patient about the diagnosis, and the treatment plan. At a time when most patients do not take in any information, because they are in shock about their diagnosis*).

I took Ueli home to wait for the operation, which was scheduled for a week later, to remove his tumors. Then – radiation throughout Christmas, and then chemotherapy. After this – (temporary) recovery, and back to international work in between new chemotherapy treatments. We knew his time was limited.

The doctor who saw us: The three doctors treating brain cancer at the cancer hospital were very competent medically, and very different in how they related to him, and to us, when he went for checkups. The female doctor always greeted him with: *“Welcome, Ueli and Ane. The pictures look fine, the treatment seems to be working.”* She was answering the burning question: **What are the results?** without delay. THEN only, she asked how he is. More relaxed after the news – he could tell her. We prepared well, and he had his questions written down. After addressing the questions, she turned to me, and asked how I was doing. This often brought out tears, as the stress and tension of always being there for him, and that he always, and naturally, was the center of the medical attention – resulted in my concerns being forgotten or overlooked most of the time. This doctor also saw me, and addressed and acknowledged the importance of my role, and of me getting support and care. She had and practiced emotional competence with a natural ease that made us both feel seen, understood, and cared for.

We always felt well taken care of when leaving the hospital after seeing her, and the nurses with her were also very supportive – they seemed to take the lead from the doctor, and we felt they were a team – who cared.

The seminar: A few months into Ueli’s treatment, we attended a seminar at the hospital for patients and their spouses. The seminar was dominated by doctors giving factual information about the disease, the prognosis and the treatment options.

We were 12 people. I will never forget the young couple in their 30s sitting across from us with what seemed like “stone faces”, with eyes full of fear. They had three children, soon to be fatherless. Their concerns were not addressed, neither were ours – about how to cope with this dreadful disease in our lives. No one addressed the emotions that were painted thickly on the faces and bodies of the participants. I gave feedback about this, and a number of other things in the seminar – but never got a reply.

I brought the issue up with our “good doctor”, and she said – *“they don’t have the skills to meet the emotions of the patients and their partners. Particularly not the fears. This is a big problem.”*

The two male doctors were focused on technicalities and treatment options, and spoke less directly to Ueli. One of them included me, sometimes, but never with empathy, and never took the initiative to bring me into



Ueli and Ane 6 weeks before he died, 70 years old.

Photo: Susan S Senstad

the conversation. He also did not show empathy to Ueli, but was friendly and straight. He answered our questions, and was effective. After meeting him we felt a bit numb, and I was sometimes angry – feeling the hurt for both of us from not having been “met”, emotionally. The nurses were also quite neutral in the meetings with this doctor – again seemingly taking the lead from him about not addressing emotions, and not showing empathy.

The other male doctor was distant. When we were there to get the news after a brain scan that showed the tumors had grown and the treatment was no longer working (=the beginning of the end), the doctor asked Ueli to come to the computer and look at the pictures of his brain. He showed him where the tumors were growing. He did not ask how Ueli was. He ignored me completely. The doctor informed Ueli about experimental treatment that might prolong his life with up to 6 months, but had many strong side effects. This was the only thing he could offer – not being capable of meeting Ueli, and me, on what we needed: Empathy.

It was a horrible meeting – not only because of the news, but because the doctor could hardly look at Ueli. The nurses were quiet and had nothing to offer. I was angry (covering up my fear), and barked a few questions to the doctor, who answered without looking at me.

After this meeting, we were both devastated, and felt very unsupported. But the cancer was real, and the remaining life had to be dealt with. Ueli decided not to have the experimental treatment.

We asked to have the remaining appointments at the hospital when our female doctor was available.

It must be incredibly tough for the health personnel to meet patients who are soon going to die, day after day. Hiding their emotions is an understandable response. I asked our female doctor how she managed to stay so present with us, give so much empathy, and not burn out? She said – the relations she built with the patients and their partners gave her a lot. She experienced the gratefulness, and the feedback about how helpful her approach was – and this gave her much energy and kept her going.

At home, we had support from the cancer coordinator and her team of a doctor and a priest. She saw Ueli and addressed his needs, and she saw me – and asked me to come to her office, alone, to discuss how I could take care of myself, to be able to be there in the best way for Ueli. AND – for myself. *“You will live on, after Ueli dies,”* she said – *“make sure you do something that gives you energy”*. She was incredibly helpful to us both, and gave medical, practical and emotional support where needed. She could see when I was so much on the edge that I would collapse if she gave me empathy. Then, she would focus on the practical issues.

We also had home care. They helped dressing and bathing him, and several other practical issues. Ueli was Swiss, and never learnt to speak Norwegian well – he worked internationally, till the last year he lived, and he and I spoke English, Swiss-German or Nepalese together. One male carer insisted on speaking Norwegian to Ueli, saying *“he has to learn the language!”* The carer spoke both English and German. But with Ueli – always Norwegian, even though Ueli did not understand. I asked him to speak English, but he refused. I got really angry – this was not a time, with few weeks/months left to live – to insist on him learning Norwegian! I complained to the home care service after this happened repeatedly and asked that he did not come back.


Most of the carers were women, and most were very good. Empathy was not common; they were mostly just practical. But that had to be enough. A few built a relation with us both, and it made a real difference to both Ueli and me when they treated him as Ueli, not just “the patient”. The small smiles and the strokes gave us much needed energy to cope with the slow dying – day in and day out.




There are so many more stories and examples.... From the institution where he spent 1-2 weeks during the last part, to give us both a break. Some of the personnel spoke very loudly to him. *“He hears well, please lower your voice,”* I said to the nurse. *“So many patients here do not hear well, so I just speak loudly to them all, it is much easier for me”*, she said. The neglect in this institution is a dark chapter, which I will leave for now.


To sum it all up – the health personnel who saw us both as people, and were genuine, present and empathetic – they were the ones we experienced as most helpful. They were direct, compassionate, and kind – not giving false hopes, but – helping us to live as well as possible, in the moment, with the support that was available. To this day, I am very grateful to them all.




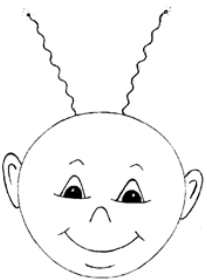
Ane Haaland, communication skills trainer, and author of the iCARE-Haaland model

Presentation slides: Comments, questions, main points to bring out

 <p style="text-align: center;">We can't always cure, but we can always care</p> <p style="text-align: center;">Relate to and handle death and dying with emotional competence Ane Haaland, Mwanamvua Boga and Ayub Mpoya with materials from Liiga Kuksa</p>	<p>Introduce the topic by asking: <i>How is dealing with death and dying important to us as health providers?</i></p> <p>Get some responses</p> <p>Acknowledge – handling dying patients and their relatives is very challenging and requires awareness and strong skills by you as health care providers. When you deal well with this, it can help patients and relatives to accept what is happening and help in their grieving. It can also help you as health care providers to process the death in a good way – with emotional competence.</p> <p>Explain that it is common for participants to experience strong emotions themselves during this module, and that it is natural to cry, when needed. This is a healthy release of emotions.</p> <p>Explain that seeing colleagues cry, or crying themselves, gives a good opportunity to practice methods of comforting each other respectfully, with empathy.</p>
<p style="text-align: center;">Referencing and acknowledging the iCARE-Haaland model</p> <ul style="list-style-type: none"> • <i>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:</i> • 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 	<p>How to reference the material is explained here.</p>
<p style="text-align: center;">This presentation is based on your own examples</p> <ul style="list-style-type: none"> • When facilitating similar presentation with health care professionals, 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 	<p>Inform participants that the materials you use come from their own examples: You should exchange the examples in the module, with those from your own participants.</p>

<p>Biomedicine, life and death</p> <ul style="list-style-type: none"> • Birth is a miracle, death is a mystery, neither fits neatly with the biomedical model....  	<p>Ask: Is this the case? Why do you think so?</p> <p>Explain: As health providers we can explain birth right from conception to delivery, but can we explain – medically - what really happens in death?</p> <p>This is a puzzle – and providers are not known for relating well to death: Is it seen as “failure”?</p> <p>Ask: How do we talk about it?</p> <p>Get responses – e.g. “Promoted to glory”, “Bed 2 packed”, “ “R.I.P.”, “Collapsed”, “Sorry he is no more”, “He is gone”</p> <p>(* see notes after slides)</p>
<p>Participant’s wish for learning</p> <ul style="list-style-type: none"> • <i>«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.»</i> 	<p>Facilitator to read this</p>
<p>Objectives</p> <ul style="list-style-type: none"> ➤ 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 	<p>Read out the objectives.</p> <p>Emphasize that the main focus is on how to acknowledge and relate to emotions – both those of the patient and her relatives, and those of the provider.</p>
<p>Resistance to talking about death?</p> <p>Discuss in groups:</p> <ul style="list-style-type: none"> • 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 • <i>Write examples on flipchart.</i> 	<p>Exercise 1: Resistance to talking about death?</p> <p>Ask: What do you think can be the reasons for our resistance to talk about death?</p> <p>Please share examples of how you talk about death among yourselves, and why there is this reluctance.</p> <p>Ask them to hang the flipcharts on the wall, and review and reflect on each other’s contributions.</p> <p>Summarize, and add from main points</p> <p>See instructions after the slides</p>
<p>Participant’s example</p> <p><i>“A lady lost her husband in the ward from HIV related conditions. This lady came to know her HIV status while</i></p>	<p>Read out the example</p>

<p><i>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 the hell that this man wanted to kill her as she remembered the big church wedding they had last year and 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?"</i></p>	
<p style="text-align: center;">Some reasons for the reluctance to talk</p> <ul style="list-style-type: none"> • Cultural traditions: Taboo to talk about death: <ul style="list-style-type: none"> – «Talking about death will hasten the process» • Medical tradition: Death is a failure • Medical training at all levels: <ul style="list-style-type: none"> – Focus on HOW to hold «difficult conversation», as technique • But lack of focus, in training and CME, on: <ul style="list-style-type: none"> – 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 	<p>Sum up or add some of these reasons if they have not been brought out during the discussion.</p>
<p style="text-align: center;">How do you relate to and deal with a patient who is dying?</p>  <ul style="list-style-type: none"> • 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 	<p>Exercise 2: Dealing with dying patients</p> <p>Introduce the exercise by acknowledging that we have probably all had to take care of patients who were dying, and that this is one of the hardest tasks of our work.</p> <p>Ask participants to share experiences of how they have done this, and write their strategies on a flipchart.</p> <p><i>It may happen that participants struggle with this exercise, if they did not take care of patients' emotions. If this is the case, acknowledging this situation and discussing why it is like this, is a good starting point for further discussion.</i></p> <p>Ask them to hang the flipcharts on the wall, and review and reflect on each other's contributions</p> <p>Ask for feedback, and summarize main points.</p> <p>See instructions after the slides</p>
<p style="text-align: center;">Respecting emotions creates trust</p> <ul style="list-style-type: none"> • «When patients emotions are respected, they develop trust and confidence both to the organization and health care providers • <i>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> • <i>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"</i> 	<p>Read out the example</p> <p>Initially the mother could not talk, but with the communication skills used, she could open up</p>

<p>HP's patience to let relatives understand information</p> <ul style="list-style-type: none"> «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» 	<p>Explain: When people have strong emotions, they often do not understand information well</p> <p>*»Pole» in kiswahili means «I am sorry for you/your loss», and is a common way of expressing condolences</p>
<p>Research evidence:</p> <p>Openness is helpful – Denial and hiding info = not helpful</p>   <ul style="list-style-type: none"> Openness from health personnel is helpful . Hiding info does not meet the dying patient's needs <p><i>Beliefs that disclosing prognostic information may result in increased anxiety and depression or destroy hope have not been supported by research findings</i></p>	<p>Sum up the discussion with this slide.</p> <p>Conclude with some questions: Should we really be open when traditions say we should not? What can we risk? How can we handle the (natural) fear of “going against traditions”, when we choose to speak more openly about death?</p> <p>Refer to what the literature says. Discuss if and how we can promote more openness to talking about death, and talk with patients who are in the process of dying.</p> <p><i>Note: This discussion goes on throughout the module</i></p>
<p>How do we cover up our fears?</p> <ul style="list-style-type: none"> 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? 	<p>Exercise 3: How do we cover up our fears?</p> <p>Ask: Do we have fears of dealing with death? Get a “yes”</p> <p>Ask: What do we do to cover up our fears? Please discuss this in your groups.</p> <p>Get feedback from groups – on one question at a time.</p> <p>Sum up the main points, adding from the list at the end of the module</p> <p>See instructions after the slides</p>
<p>Automatic reactions when we are fearful of death</p> <ul style="list-style-type: none"> Common reactions: <ul style="list-style-type: none"> – Withdraw – Be impersonal – Be cynical – Pretend we don't care Purpose: <ul style="list-style-type: none"> • Protect our (vulnerable) feelings Alternative: <ul style="list-style-type: none"> • Awareness; presence 	<p>Review the points so far: These are common automatic reactions, and they have a purpose we may not be aware of: To protect us from feeling the pain</p> <p>The alternative is to use emotional competence: Recognize the emotions, step back, and be present with the dying person – and/or the family We will continue to work on these skills throughout the module</p> <p>Ask if they have questions or comments so far</p>

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?

Exercise 4: Dying patients' fears and needs

Introduce the exercise by acknowledging that fear is a strong emotion when relating to death – both for the provider, and for the patient

Ask: Please recall, in your groups, patients who knew they were dying, and discuss what you think they were afraid of, and what their needs were.
Get feedback from groups – on one question at a time.

Sum up the main points, adding from the list at the end of the module

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**

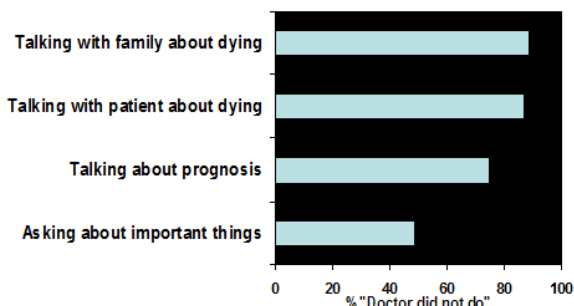


Naming and recognizing the fear can reduce it.

Explain: From research with patients who are dying, these are common fears they express.

Read out the slide – relate it to what participants have said in response to exercise 4.

Communication With Physicians: Severe COPD "**Doctor Did Not Discuss**"



Curtis, Eur Resp J, 2004; 24:200

Explain: At least 90% of the doctors in this study did not talk with the patient about dying. They don't know how to do it.

Emphasize the seemingly common habits of providers: The patient wants us providers to talk with them, but unfortunately – we don't





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?**


Review some of the reasons for patients misunderstanding and not initiating discussions when they are in their last phases of life.

<p>Study on cancer patients: Needs of dying patients</p>  <ul style="list-style-type: none"> ➤ 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 	<p>Read out the slide: Other results from research</p> <p>Relate this to their discussion – did they have other points?</p> <p>Conclude: The main need of a dying person is that they know you (and/or someone close/someone they trust) will be there for them, listen, and talk to them when appropriate.</p> <p>Emphasize: The fear of being alone is often strong.</p>
<p>«...I am nothing, but my illness»</p> <ul style="list-style-type: none"> • <i>“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”</i> 	<p>Read out the text</p> <p>Ask: What does this mean to you?</p> <p>Get their suggestions, and discuss the need to see the patient as a person, a fellow human being.</p>
<p>What do patients know, and want? Studies show...</p> <ul style="list-style-type: none"> • 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 	<p>The needs of the patients are clear, and their needs are not being met</p>
<p>Denial: a natural protection</p> <ul style="list-style-type: none"> • 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  	<p>Explain and discuss: Your ability to practice emotional competence – and especially the skills to recognize and handle fear – can make a big difference to patients and their relatives.</p> <p>Let participants reflect together on how they can do this.</p>

<p>“Good Death”: components</p> <ul style="list-style-type: none"> • Pain and symptom management. <ul style="list-style-type: none"> – Fear dying unattended and in distress • Clear decision-making. <ul style="list-style-type: none"> – Empowered by participating in treatment decisions • Preparation for death. <ul style="list-style-type: none"> – Want to know what to expect and plan • Completion. <ul style="list-style-type: none"> – Faith, spiritual, life review, conflict resolution, time with family and friends, saying goodbye • Contributing to others. • Affirmation of the whole person. <ul style="list-style-type: none"> – Understanding current condition in the context of life, values, and preferences <p style="text-align: right;"><i>Dr Jason Ward Consultant in Palliative Medicine Mid Yorkshire NHS Trust The Prince of Wales Hospice 15</i></p>	<p>Read out the slide: Other results from research</p> <p>Ask them to reflect briefly in groups, how this relates to their own experiences, and to their culture: The example here is from the UK.</p> <p>Ask for comments and reflections</p> <p>Main points: Patient may want you to speak; they may want e.g Completion, by praying. They may have had arguments, and want to “Clean up” – so they can go in peace. They may want relatives to come. They may have other needs.</p> <p>Note to the trainer: Some of these points may be controversial in some cultures, and it is useful to bring this out: The point is – there is no “right answer” that fits all situations, and all dying patients.</p> <p>By discussing these points, the group can continue to explore and share what they have found to be the most helpful strategies when relating to patients at the end of their lives, and to their grieving relatives.</p> <p>Sum up by reminding them to be human beings, and be present and respectful</p>
<p>This was from research in 2003. What now, almost 20 years later?</p> <ul style="list-style-type: none"> • 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 	<p>Explain: Changing practice takes time.</p> <p>We have looked at the literature to find out if and how practices regarding giving patients and relatives information and talking with them about death and dying, has changed since we started working with this theme.</p> <p>It seems like there is little change.</p> <p>HCPs are still very much afraid of relating openly to end of life issues.</p> <p>It seems like they are also not getting much help to learn the necessary skills, from their training institutions.</p> <p>When you practice in a different way, speaking openly, with emotional competence – you are meeting the needs and wishes of the patients – and contributing to a much needed change.</p>

<h2>Attitude that needs changing -</h2> <p>From -</p> <ul style="list-style-type: none"> • «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»  <p>To –</p> <ul style="list-style-type: none"> • «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» 	<p>Sum up the learning – ask participants to reflect together on how they can contribute to this change.</p> <p>Reflect together</p>
<h2>What influences how health providers deal with death and dying?</h2>  <ul style="list-style-type: none"> • Fears and anxieties • Past experiences • Culture • Our attitudes • Lack of skills to handle emotions 	<p>NOTE: Animate this slide – show only title</p> <p>Let participants discuss briefly in groups</p> <p>Ask: What is it that influences how we as providers deal with death and dying? How does our culture influence how we deal with death and dying?</p> <p>Main points (adjust for own culture)</p> <p>Our culture does not allow us to talk about it – it is taboo (witchcraft can be seen to influence this: “if you talk about death – it will happen”)</p> <p>Explore other cultural aspects (if not covered in group works above), e.g. “Men don't cry”, it is weak to be crying</p> <p>Acknowledge points on slide</p>
<h2>Taking care of providers' own needs</h2> <ul style="list-style-type: none"> • How do you take care of your own emotions in this situation? • Discuss how you can help each other <ul style="list-style-type: none"> – recognise, – acknowledge, – respect + – take care of feelings - • when dealing with death and dying 	<p>Exercise 5: Taking care of providers' own needs</p> <p>Ask them to discuss and share experiences of how they take care of their own needs and emotions when relating with patients and their relatives in this situation.</p> <p>See purpose, procedure and points at the end of the module.</p>
<h2>Crying with patients – with awareness</h2> <ul style="list-style-type: none"> • Many HPs are afraid of crying with patients, or with relatives who lost a dear one • Why do we fear crying? <p>Crying can have positive effect:</p> <ul style="list-style-type: none"> • Releases stress and tension • Patient and relatives feel comforted • Crying with awareness = healthy for HP, and patient  	<p>Ask them to buzz: Why are so many of us afraid of crying?</p> <p>Main points:</p> <p>We want to look courageous. If you cry or show tears – does it mean you have not qualified as a professional, that you cannot control emotions?</p> <p>Does it mean you are weak?</p> <p>Many go to a private place to cry a little, then bottle up the feelings.</p> <p>Many don't cry or show tears at all –maybe especially men</p> <p>Crying can have positive effects; release tension Don't be afraid of crying – what matters to the parent/family is that you are present – not that</p>

	<p>you are courageous Crying is honest, can create trust HP showing her “softer side” will help balance and contradict attitudes and opinions many people have had of nurses: <i>“You – you are a nurse, you should be used to seeing people dying, you should not cry”.</i> <i>„In the general public –many equate nurses with police... Our hearts are hardened. We are forgetting that we are also a human being.”</i></p> <p>See example at the end of the module Discuss, and reflect</p>
<p>Core attitudes and skills when patients are dying</p> <p>In Kilifi, providers say the following is helpful:</p> <ul style="list-style-type: none"> • Awareness and presence <ul style="list-style-type: none"> – 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 <ul style="list-style-type: none"> – Put aside personal preferences – Don't be critical – Be tolerant, patient, flexible – Listen, with awareness • Take care of your own emotions <ul style="list-style-type: none"> – When appropriate, get support for yourself 	<p>Explain: Participants in communication courses in Kilifi have found that skills to recognize and manage emotions are central when relating to dying patients, and their relatives. And – for themselves</p> <p>Read out the slide Ask for comments and reflections Discuss</p>
<p>Communication with dying Patients: Competencies needed by providers</p>  <ul style="list-style-type: none"> • Listen to patients • Encourage questions from the patient • Talk with patients in an 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 <p>Curtis, J Gen Intern Med, 2000;16:41</p>	<p>Explain: Research has shown that these are skills needed by providers. Our participants in Kilifi agree with these points, and had their own points to add</p>
<p>Participant's example</p> <ul style="list-style-type: none"> • <i>“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.</i> • <i>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> • <i>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”</i> 	

<p>Experiences and reflections of providers in Kilifi</p> <ul style="list-style-type: none"> • 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 	<p>Read out the example of how the lead trainer in Kilifi has used the good communication skills to take care of a dying patient and his parents.</p> <p>Example is found on page 9, just before the slides.</p> <p>Ask for reflections and insights Discuss, and conclude</p>
<p>Summary</p>  <ul style="list-style-type: none"> ➤ Communication about end-of-life care <ul style="list-style-type: none"> ➢ Often poor and <i>not meeting patients' needs</i> ➢ 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 <ul style="list-style-type: none"> ➢ Recognizing emotions, step back. Listening with empathy, being authentic, honest and sensitive 	<p>Sum up the module with this slide.</p> <p>Conclude:</p> <ul style="list-style-type: none"> • <i>We all have to learn how to meet the needs of the dying patients better – by managing our own fear, stepping back from it, and being present with the patient.</i>
<p>Examples and references from the literature</p>	<p>A number of slides with references to literature and relevant articles and reports have been added in the pptx presentation.</p>

Facilitation notes, exercises and examples

Facilitating an example from a participant - slide 2

Example of a discussion with a participant, which functioned to gently lead the participant to discovering that his way of responding to a bereaved mother, did not take care of (or even acknowledge?) her emotions.

Trainer: How do we talk about death, when a patient has died?

Participant: We say e.g. he is “promoted to glory”, or “R.I.P”

Trainer: Is this what we say to the bereaved?

Participant: Yes, I will e.g. tell the mother that her son has been promoted to glory, so she should not worry. Is this not a comfort to the bereaved?

Trainer: Can you tell me about an emotion the bereaved mother will feel?

Participant: I think she must be feeling pain

Trainer: Will you have addressed this by saying the son has been promoted to glory?

Participant: No

Trainer: We can see that **your intention** was clearly to take care of the mother’s emotions, but – that your method did not quite do this. We are not familiar with relating to patients’ and relatives’ emotions, so this is a skill that needs to be learnt. We will discuss more about this in the module today, as well as in other modules in the next days.

NOTE: *The trainer is careful not to criticize the participant for his habit, but rather acknowledge his intention to be helpful and compassionate. Through being asked questions about the potential effect of his statement, on the mother, the participant was guided to reflect – and find that most probably, his (habitual) way of responding did not meet the emotional needs of the mother.*

We did not explore how the participant himself felt.

Exercises

Exercise 1: Resistance to talking about death

Purpose: To strengthen awareness of and skills to explore cultural reasons for the way they talk about death, and for the way they don’t talk about it – and reflect on the influence of these “hidden rules” on the way they handle their patients – and themselves, in relation to this issue. Furthermore, to share examples of how they talk about death, often in an impersonal and cynical way (“bed 2 packed”), and strengthen awareness of how such expressions can function to hide their emotions. Finally, to strengthen awareness of the effects of how they talk and act, on patients and relatives, and on themselves.

Procedure:

1. **Introduce the exercise** by asking them if it is true that there is resistance to talking about death in their culture? (most likely, they will say yes). Ask them to reflect about “culture” – are we here talking about the national (or regional) culture, or about the medical culture, or both?
2. Then, ask them to **discuss** the questions on the slide, in their group:
 - Is there resistance? In national culture? Medical culture?
 - What could be the possible reasons for the resistance?
 - Share examples of how you talk about it (give an example so they know what you mean – e.g. “Bed 2 packed”); write on flipchart
 - Hang the flipcharts on the wall
3. **Ask them to review each other’s flipcharts, and reflect.** Ask for comments and reflections. Ask which function the distant/cynical “labels” have on the providers/colleagues, and on the patients/relatives.

4. Sum up the main points

Main points to bring out:

- Culturally, there are many reasons for not talking about death – e.g. that it is a bad omen to talk about it, that it will hurry death on if you mention it before the person is dead. Witchcraft may be influencing how people think, and especially their fear about death.
- In the medical culture, reasons could be that death is seen as a “failure”, and therefore it is not acknowledged, or talked about. The provider asks herself – “where did I go wrong?” “What did I not do?” – which are necessary questions – but only part of what has to be done. Death is treated as a medical event, and the emotional aspects are ignored, or left out.
- Providers have not learnt to talk about or relate constructively to emotions, especially to fear - and to death. The automatic reaction is to push away/cover up the emotions by e.g. being impersonal, cracking jokes, laugh, pretend you are busy, or behave as if nothing happened; ignore it. Such expressions are experienced as extremely disrespectful and hurting by the parent/relative.
- By “covering up” death by talking casually about it (e.g. R.I.P., Salama salama, Promoted to glory, Bed 3 packed), we postpone or suspend the emotions – which means we don’t REALLY deal with it. The consequences can be serious - we will deal with this later in the module.
- Denial of the (upcoming) death, fear to face it, is a common reason for the resistance to talk about death. The denial can be conscious, i.e. they KNOW what is coming, but choose not to relate to it/not get the emotions involved/show control. It can also be subconscious, i.e. they don’t know what to do, so they try to avoid talking about it, or avoid acknowledging the seriousness of the situation.
- Providers often feel genuinely sorry when a patient dies, but – they lack the skills to deal with it. Many also lack awareness about what the relatives are going through, and skills to show it in a respectful way by using empathy, compassion, comfort and care.

Exercise 2: Relating to and dealing with a patient who is dying

Purpose: To strengthen awareness of the needs and concerns of dying patients, by allowing participants to share experiences of how they relate and deal with dying patients and their relatives. Furthermore, to strengthen awareness of participants’ own fears, needs and reactions when faced with dying patients, and strengthen key skills to relate and deal with patients and their relatives: staying present, showing respect, and showing empathy, compassion and care.

Procedure:

1. **Introduce the exercise** by asking them to share experiences on how they related to patients who were dying, and how they took care of the emotional needs of the patients (and/or parents/ relatives, if the person dying was a child).
2. Ask them to **write the strategies they used, on flipcharts**, and hang on the wall
3. **Ask them to review each other’s flipcharts, and reflect.** Ask what are common features in the strategies, and ask for comments and reflections. Review one or two examples, if appropriate.
4. **Sum up the main points**

Main points to bring out:

- Seeing a colleague cry, or crying yourself when discussing this issue, is a good opportunity to practice empathy and to comfort each other.
- Fear will usually be the main emotion present, for patients, relatives and the provider. Acknowledging and respecting this emotion can make it a bit easier to relate to the situation, and to learn to step back from the fear to communicate with respect and compassion.

- Being aware of the real needs of patients, colleagues and yourself when faced with dying patients, is very hard. Managing to stay present with the emotions, while not getting “lost” in them, will be healing to the patient, and to the provider. This is good professional caring.
- Showing respect and being present are key skills – and a main part of the strategy, together with empathy, compassion, comfort and care.

Exercise 3: How do we cover up our fears?

Purpose: To strengthen awareness of the natural reaction of fear as a main emotion present when faced with a patient dying. Secondly, to strengthen awareness of how providers cover up these fears, and explore reasons why they do so, consciously or subconsciously (denial). Thirdly, to share experiences of their own emotions when dealing with dying patients. Finally, to reflect on how appropriate, useful and respectful to providers’ own needs the present strategies are, and explore options for taking better care of these fears – while still being able to help the dying patients.

Procedure:

1. **Introduce the exercise** by acknowledging that it is very natural to feel fear when faced with the impending end of a life.
2. Ask them to **discuss** the questions in their group:
 - How do they cover up their fears? How aware are they of doing this (are the strategies conscious or subconscious?)
 - How effective are their strategies – in the short run, and in the long run? What could be consequences of these strategies?
 - Are the strategies respectful to themselves? How?
 - Are there options/strategies to take better care of themselves, while still taking care of the patients’ needs?
3. **Ask for feedback**, and structure the discussion to come up with the main points (see below). The structure could follow the questions asked on the slide, unless there is another natural way the discussion flows.
4. **Sum up the main points**

Main points to bring out:

- Providers cover up fears by e.g. avoiding interaction with the patient, asking a colleague to do the job, or say they are busy. Some feel panick, just walking around without not doing anything constructive. Others give false reassurance to the patient – telling them they are getting better, or not to worry – to avoid talking about the difficult subject of death.
- When a patient is feeling very vulnerable, she or he is less likely to take initiative to ask questions – unless invited to do so.
- Facing death can make providers feel vulnerable, feel that they are not invincible, they are also mortal. This is very uncomfortable, and it is natural to want to avoid the emotions and cover them up.
- In the short run, it may feel protective to avoid dealing with the emotions, and facing the fear. In the long run, the strategies used are not effective in protecting the provider from the pain – as covering it up without dealing with it at some stage, will usually backfire (sickness, burnout). By covering up, the provider does not respect her/his own emotional needs, and is usually then not able to meet the emotional needs of the patient and their relatives.
- Being aware of and acknowledging the fear, respecting it and dealing with it with compassion and care, is usually a better way to manage these strong emotions – for the provider, and for the dying patient and his/her relatives.

Exercise 4: What are patients’ fears when they are dying?

Purpose: To strengthen providers' awareness and understanding of common fears experienced by dying patients, by sharing experiences on how they have handled dying patients, and reflecting on what their fears could have been. Furthermore, to strengthen awareness of what the patients' needs could be in such situations, and what providers can do to meet these needs.

Procedure:

1. **Introduce the exercise** by asking them to again reflect on patients they have related to, who were dying: what could they have been afraid of, and what could be their needs?
2. **Ask for feedback**, and structure the discussion to come up with the main points (see below).
3. **Sum up the main points**

Main points to bring out:

- Patients have many fears – see next slide for common ones
- When they have small children, the fears may be especially strong about these
- When patients do not feel they have anyone they can trust around them, they suffer very much
- Provider needs to separate between his/her own fears, and the patients' fears
- Many providers do not want to get involved, as it evokes strong feelings in them.
- You don't want it to happen, but it has to happen
- Our responsibility as health providers is to acknowledge these fears, understand the emotions patients are going through, and be there for them by being aware and present, showing empathy and compassion. We can always care, and help in the process
- We all have to learn how to meet the needs of the dying patients better – by managing our own fear, stepping back from it, and being present with the patient.

Exercise 5: Taking care of providers' own needs

Purpose: To strengthen awareness of strategies that can be used to take care of providers' own emotional needs when dealing with patients who are dying (and their families), by sharing strategies they use now, and reflecting on how effective the strategies are to meet these needs. Furthermore, to strengthen awareness about crying as an important strategy, and the benefits of this strategy to relieving stress, anxiety and grief when dealing with death and dying. Finally, to strengthen awareness of potential consequences of not meeting their own emotional needs over time when facing these difficult situations, and discuss alternative strategies.

Procedure:

1. **Introduce the exercise** by acknowledging that taking care of their own emotional needs is essential for a provider to be able to deal respectfully with death and dying over time, and – that the discussion today, as well as our knowledge about how we relate with the topic in our daily work, shows that we have a lot to learn, to handle these difficult moments.
2. Then, ask them to **discuss** the questions on the slide in their groups, and share strategies they use to take care of their own emotions.
3. **Ask for feedback**, and structure the discussion to come up with the main points (see below). The structure could follow the questions asked on the slide, unless there is another natural way the discussion flows – based e.g. on examples participants contribute.
4. The assistant facilitator can write strategies on flipchart, and hang this on the wall – as a reminder of good strategies. You can also make the point here that we do this – as we know many participants may forget some of the strategies, as many have strong emotions around this issue – and then they will remember information less effectively.
5. **Sum up the main points**

Main points to bring out:

- Strategies participants use are e.g. sharing the sadness with a colleague; go somewhere private to cry, then come out and talk with the parents/relatives; praying; crying with the parents/relatives, while still maintaining the professional role; taking the mother to the ladies' room, giving her a tissue; not blame the colleague that she is crying. Be there to encourage and comfort her, and show respect for her emotions, and show empathy.
- The main strategy is to recognize and acknowledge the fear, accept it, step back appropriately to be there for the family by being present and showing respect, and then take care of your own needs.
- Ignoring your own needs over time can make you protect yourself (automatically, without awareness) by not showing emotions to the patient or family who is facing death. This will feel like a rejection by the patient and family, and will add to their grief. In addition, it will make it more difficult to deal with your own grief. Bottling up grief over time can lead to stress, conflict, burnout and physical illness.
- If there is no or little time during the shift to take care of own needs after a death, and no provision from your workplace to help you do so, it is wise to take care of the need at home – by talking with a good friend, listening to good music, or doing something that makes you feel good.