CANADIAN VirtualHospice Portailpalliatif CANADIEN

Building capacity to support grieving families in the ICU: Online training for ICU clinicians

Accompanying content document

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Building capacity to support grieving families in the ICU: Online training for ICU clinicians

Overview

"Grief and trauma are rarely directly talked about by ICU clinicians; we tend to learn about it by osmosis". - ICU Nurse

Families struggle with the intensity of the ICU. Most will have little or no healthcare knowledge, they will be trying to come to terms with a sudden and life-threatening health emergency of someone they care about, and they may be asked to make decisions they don't feel prepared to make. This often results in psychological trauma and grief.

These modules help ICU clinicians to better understand and support families in distress, specifically in clinical situations when patients die. While you can't always prevent a death, you may be able to reduce the impact of psychological trauma. Integrating some of this content into your practice may require you to stretch beyond your comfort level as you learn new ways to interact with and support ICU families experiencing grief and psychological trauma. By using timely and sensitive psychosocial interventions, you'll help families cope as well as make a long-lasting difference for years after the death.

Module 1, Understanding and responding to families' grief and trauma, provides (1) information about how families experience and express trauma and grief; (2) assessment strategies for grief and trauma risk; and (3) suggests ways to engage constructively with families within the context of grief and trauma.

Module 2, Strategies for addressing traumatic grief, describes specific interventions that you can use to support families, along with strategies for dealing with problematic and less common issues that may arise.

Module 3, Supporting children visiting the ICU, contains information about how best to support children visiting your ICU.

Module 4, Understanding and responding to vicarious trauma, examines the impact of grief and trauma on ICU staff and offers suggestions for how you and your team can constructively respond to the challenges of your work.

A note about language:
Throughout these modules, "**trauma**" is used to refer to "psychological trauma." "**Family**" is used to refer to members of the patient's primary support network, including biological and chosen family and friends.

This document elaborates on and provides further detail on the topics covered in the ICUGrief modules. The ICUGrief modules are designed for experienced ICU clinicians as well as students and early-career clinicians. The content is interview- and evidence-informed and was developed and peer-reviewed by national experts in grief, ICU and related fields.

Module 1: Understanding Grief and Trauma

Introduction

"That month we were in ICU was basically a different storm every day". – Family member of ICU Patient

"One of the hardest parts of the job is the family care and not the patient care". – ICU Nurse

Recognizing and assessing the signs of grief and trauma are the first steps in effectively supporting family members and preventing long-term complications of grief.

By completing this chapter, you will be able to:

- Summarize how grief and psychological trauma (referred to as "trauma") intersect in the ICU setting.
- Describe different ways families experience and express grief and trauma.
- Identify strategies you can use to build trust and establish good working relationships with families.

Module 1, Chapter 1: What is traumatic grief?

Introduction

"Watching my brother break down and lose hope for the first time was one of the hardest things I have had to go through". - Family member of ICU patient

"This is the most intense place I have ever worked. Trauma is at the centre of everything we do with patients, families, and staff. But those of us who work in ICU usually don't get much training in this regard". - ICU Spiritual Care Provider

Psychological Trauma, hereafter referred to as "trauma", results from an incident that is seen to be both unavoidable and threatens the person with actual death, possible death, or serious injury to themselves or others.

Grief is an emotional reaction to loss with accompanying psychological, cognitive, behavioural, and physical manifestations.

Grief and trauma tend to overlap substantially although there are important differences between them. Whereas grief tends to be linked to various forms of loss, trauma is often associated with a threat of dying. Trauma sometimes blocks the grieving process.

Most traumatic experiences include loss, and the majority of losses have a traumatic element. The bridge that links grief and psychological trauma is *traumatic grief. Traumatic grief* is the state of having suffered a loss of someone when grief and mourning over the death are complicated or overpowered by the traumatic stress brought about by the particular circumstances.

Because the ICU is an environment saturated by grief and trauma, families inevitably experience these phenomena to varying degrees. These experiences, and their accompanying cognitive, emotional, behavioural, and physical expression, are *common and normal* elements of the family experience in an ICU.

Understanding the family's grief

"Watching my brother break down and lose hope for the first time was one of the hardest things I have had to go through". – Family member of ICU patient

You may see varying expressions of grief from admission through after a person has died. When families become aware that death is probable or certain, they often experience **anticipatory grief** and express some degree of psychological distress. Grief is experienced along a continuum, from minimal to severe levels of distress, and may fluctuate, from day to day or even hour to hour. Similarly, people express their grief differently, often influenced by sociocultural factors, such as ethnicity, sexual orientation, religious or spiritual inclinations, education, gender, family history, etc. Grief may be expressed "out loud" as mourning, it may be barely observable, or anywhere in between.

Anticipatory grief itself refers to psychological distress experienced in the present but influenced by previous losses in tandem with anticipated future losses.

Understanding the family's trauma

Trauma occurs when a person faces imminent death or serious injury to themselves or others. While the occurrence of death may be somewhat routine to you, the threat or the actuality of dying is new and always present and visible to families.

When some families witness events that are shocking to them, such as a drastic medical intervention or a cadaver being moved, psychological trauma may occur. This can cause a traumatic response, which instantaneously drives the brain and body into a kind of "survival mode" that overpowers a person's usual coping abilities. This can create significant psychological distress and dysfunction.

Trauma can also lead to an existential crisis of sorts, undermining three implicit assumptions people have about the world:

- The world is a safe place.
  - *"I always felt that the hospital was a safe place, but after seeing so much in the ICU I'm not so sure I can ever go back".*
  - *"I always believed that God would keep my family safe but after his death I am left with many difficult questions".*
- It's always possible to explain and make sense of events.
  - *"Why did he have this accident? This question keeps rolling around in my head and I can't stop it".*
- Good actions lead to good outcomes.
  - *"He was such a good person, why did this have to happen to him"?*

It may not be apparent to you that a family is experiencing trauma, but this doesn't mean that it's not happening. The following sections will help you recognize how families experience and express both grief and trauma. There are often elements of grief that occur in the context of trauma, and there are often traumatic aspects in grief. As a result, there are symptoms common to both trauma and grief.

Cognitive effects of grief and trauma

Families see people who are tied down, looking awful, puffed up with fluid. It is very traumatic, for example, when they see a young person who is broken from head to toe". – ICU Social Worker

Cognitive effects common to grief and trauma

"I did not think he would die, but I also knew that going to the ICU was where you went to die".
- Family member of ICU patient

Many families find themselves in a state shock and uncertainty. This can significantly impair your communication with them. You may see any (or all) of the following:

- Forgetfulness
- Denial of what is happening
- Difficulties retaining clinical or other information-Shock
- Distractedness, inability to focus
- Absent-mindedness
- Overcompensation

Cognitive effects distinct to trauma

"In the intensity of the ICU moment, you cannot integrate all the information you want to know". - Family member of ICU patient

Like grief, trauma effects many aspects of human thinking and behaviour. In certain circumstances, grief can co-occur with trauma, with the higher end of the continuum manifesting in the development of both Post Traumatic Stress Disorder (PTSD) with concurrent complicated grief which often indicate the need for a professional referral. **Post-traumatic stress disorder (PTSD)** is a diagnosable psychological condition that occurs in response to a very disturbing event, either experienced or witnessed. C**omplicated-prolonged grief** refers to a clinical profile of heightened psychological distress that continues at least 6 months to a year after a significant death occurs.

These cognitive effects include:

- Intrusive and vivid images linked to a difficult episode. These images can occur while the person is awake or asleep even if they didn't directly witness the event but heard about it from others.
- Concerted efforts to avoid troubling thoughts, memories associated with the traumatic event
- Incapacity to recall significant parts of the traumatic event
- Persistent and overstated negative thoughts about oneself, others or the world (e.g., "No one in the health care system can be trusted.")

Two distinct psychological phenomena that are common and not usually an indication of psychosis are:

- *Depersonalization*: When a person feels separated or detached from their mind, feelings, or body. Some people feel that they are observing themselves from outside their own body.
- *Derealization*: feeling apart or removed from one's surroundings such that one feels they are living in a dream.

Communicating with the family

You may need to have multiple conversations with a family member about a clinical issue for the details to sink in.

Emotional impact of grief and trauma

"Families have enormous grief reactions. Some will fall to the floor and scream. Others will not be able to speak; a few will say that they cannot feel their hands or feet. We see people dissociate and decompensate constantly. Many families will sort of "check out;" they are not able to absorb what has happened". – ICU Nurse

End-of-life experiences are likely to elicit deep and mixed feelings. Family member may express intense emotions, and different emotions may occur simultaneously, whereas others may prefer to keep their emotions to themselves and it may not be obvious that they are struggling internally.

One of the most challenging emotions you may face is anger. Families are under stress and may sometimes direct anger towards you, especially if they feel the care of the patient has been inadequate. Remain calm and remember that the anger is often a secondary emotion to grief and trauma. It is the family member's intense and (redirected) emotional response to their loss, not a personal attack on you.

Emotional reactions common to grief and trauma

"I never thought I had that depth of feelings, but they burst out of me in a way that was sometimes scary". - Family member of ICU patient

Many families find themselves in a state of shock and uncertainty. This can significantly impair your communication with them. You may see any (or all) of the following:

- Sadness
- Numbness – not knowing what or how to feel
- Not being able to find words; feeling it's surreal.
- Sadness – tears, sobbing.
- Anger, frustration – shouting, making accusations.
- Anxiety/panic attacks.
- Fear about future outcomes, decision-making, pain & symptom management.
- Worry about being judged by you or other staff about how they are dealing with the situation.
- Conflicting feelings – e.g., relief in knowing that the patient's suffering will soon end while concurrently experiencing guilt or self-reproach for feeling this way; wondering if they did "the right thing" after death has occurred.

Emotional reactions distinct to trauma

"I was tearing out my hair when they told me she way dying. I could not believe what was happening". - Family member of ICU patient

Like grief, trauma affects many aspects of human thinking and behaviour, such as:

- Flood of emotions - being completely overwhelmed and emotionally devastated.
- Dazed and frozen - Total lack of feelings.
- Highly negative emotional states including blaming oneself that the patient died, reporting a sense of horror, and/or extreme feelings of guilt or shame.

A minority of family members will have atypical and even paradoxical emotional reactions, such as laughing inappropriately or displaying seemingly unrelated emotions in rapid succession. Uncommon emotional reactions are common under moments of intense stress and not necessarily something that warrants clinical attention. In very rare circumstances an emotional reaction may be indications of pre-psychosis that warrants professional intervention.

Behavioural expressions of grief and trauma

"I could not believe what I was seeing. I never saw people hooked up to machines and look so sick... I found myself thinking about the events in the ICU years afterwards". - Family member of ICU patient.

Behavioural expressions common to grief and trauma

"I was always edgy. I could barely sleep and eat. I felt as though I needed to be awake for everything. I especially did not want to be asleep the moment he died". - Family member of ICU patient.

People may behave in atypical ways when they are grieving. Some behavioural expressions of grief you may see while working in ICU include:

- Hyperactivity
- Social withdrawal and isolation
- Disruptions to sleeping and eating – e.g., strange dreams or nightmares; over- or under-eating.
- Avoidance behaviours – e.g., avoiding the patient's room or not coming to the ICU.
- Social withdrawal and isolation – e.g., minimal communication or interaction with others.
- Excessive or a lack of dependence on the clinical team
- Making impulsive decisions
- Engage in risky behaviours

- Become more aggressive

Behavioural expressions distinct to trauma

"His death was very sudden. I screamed and fell to my knee., It was like a moment from a tv show but it was happening to me". – Family member of ICU patient

Traumatized people may behave in abnormal ways. In addition to the phenomena of 'fight' or 'flight', a third very common response is to freeze. They may become rooted in place, unable to speak or move. Family members may also exhibit the following behaviours:

- Tremble or develop an exaggerated startle response, such as jumping when you casually enter the room.
- Extreme problems with sleep
- Significant avoidance behaviours (e.g., refusing to enter the patient's room)
- Particularly self-destructive behaviour
- Exceeding aggressive behaviour (e.g., making threats)

Physical manifestations of grief and trauma

"I could not believe what I was seeing. I never saw people hooked up to machines and look so sick... I found myself thinking about the events in the ICU years afterwards". - Family member of ICU patient

Physical manifestations common to grief and trauma

"My stomach was in knots from the moment we arrived in ICU". - Family member of ICU patient

Bodily ailments are very common in grief. Some typical physical manifestations common to grief and trauma include:

- Hollowness in the stomach.
- Tightness in the chest and throat.
- Oversensitivity to noise.
- Dry mouth.
- Muscle weakness or tension.
- Lack of energy.
- Gastrointestinal distress.
- Lack of coordination, dizziness, or fainting.
- Restlessness

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Physical manifestations distinct to trauma

"What is my personal definition of trauma? The adrenaline rush, being terribly frightened, and having residual negative emotions that last for years". – Family member of ICU patient

When traumatized, the body usually responds by going into a kind of hyperarousal. This can include a flood of adrenaline. This heightened state is usually accompanied by symptoms such as:

- Trembling
- Periods of elevated heart rate (tachycardia)
- Persistent gastrointestinal distress
- Sweaty palms
- Difficulty catching one's breath
- Persistent muscular and joint pain
- Severe headaches or migraines

These can be coupled with extreme fatigue and exhaustion.

Module 1, Chapter 2: Strategies to assess and engage with families

Introduction

"In ICU, suddenly the family becomes our new patients and we are taking care of everyone in the room all at once". – ICU Nurse

In this chapter you will learn strategies for communicating and building relationships with families. Your ability to assess their needs and risks depends on this. As the clinical situation evolves, new stressors may be placed on the family. Ongoing monitoring of how the family is managing and coping with the associated stressors is important. Building a positive relationship will facilitate good communication, and strong trust, both of which can help prevent traumatic grief. As death approaches, the family's psychosocial needs often exceed those of the patient. Most families will benefit from increasing levels of support. Some of the material presented below will be useful during family meetings.

Identifying the family spokesperson

"I am interested in finding the identified leader of the family who will help guide family members through the process. Working together with this particular family member helps as they have a history and way of speaking to the rest of the family that we just don't have". - ICU Nurse.

It can be very helpful to find someone who is the usual spokesperson of the family and can act as a conduit for information between the family and the team. However, be aware of family dynamics to ensure that the rest of the family is comfortable with this arrangement and be aware that this role can put great pressure on the person and can adversely affect them. In such circumstances, you may need to identify an alternate who can share the responsibility.

It's common for a spokesperson to be a health care professional. Remember that this person is first and foremost a family member who will need your help in managing this dual role.

Establishing a good foundation

"It was the relationships with the people and the care they provided that was the most important". – Family member of ICU patient

The value of a good first impression cannot be understated. Welcome the family to the unit. You can say, "We are here to work with you and we'll do the best we can to support you and your family while you are with us".

Families will have varying reactions when they first arrive. While this is a familiar work environment to you, for families it is much more personal and foreign.

Below are a few common causes for family distress upon ICU admission:

- The patient is newly admitted to hospital.
- The patient was recently diagnosed with a life-threatening illness or acute health crisis.
- There has been a progression of an underlying disease.
- The patient is unresponsive.
- The patient has delirium.
- The patient is critically injured or made a suicide attempt.
- The family member does not understand why the patient was admitted or has been given conflicting information.

Connecting with families

"My goal is to try to make sure the family doesn't feel like an outsider, but instead to give them a coherent and realistic story they are a part of, can understand, and can contribute to". – ICU Nurse

If you and your team can forge a strong relationship with a family prior to a patient's death, this can lessen the risk of traumatic grief.

Establishing a positive relationship with families is very much an intuitive process, although you can learn from experience and through observing others. Here are a few things to keep in mind:

- Listen intently, give families your full attention, and don't interrupt them unnecessarily.
- Remain flexible and open to discussing relevant topics with the family.
- Maintain a respectful attitude.
- Be as heartfelt, friendly, and affirming as you can.
- Be predictable, honest, and trustworthy.
- Allow for moments of silence.

Overall, families tend to respond better to collaborative rather than top-down styles of engagement by staff. This can be challenging, especially in situations where you may have knowledge and expertise that the family isn't ready to receive. Try to follow their lead in terms of what news they are ready to receive as much as you can without compromising care.

You can involve the family by asking if they would like to help with the patient's care. Some families may be able to assist whereas others may be frozen and unable to engage. Determine what they are capable of and comfortable engaging in, for example combing hair or applying

Establishing safety and trust

"I was very naïve about how the ICU works...I came away realizing how important it is for families to feel safe". – ICU Family Advisor

Trust between family and staff is established through positive, respectful and honest conversations, actions, and behaviour. Look for small ways to give a personal touch in your care. It's possible to be respectfully curious while maintaining professional boundaries.

What helps to quickly build trust and safety in a new relationship with families in the ICU?

- Directness.
- Compassion.
- Genuineness and authenticity.
- Simplicity.
- Openness.
- Transparency: If you don't know the answer, it's best to just say so and add that you will try to find out and follow up with them once you have the answer.

What prevents building trust and safety with families?

- Insincerity.
- Withholding information.

- Rushing and conveying a lack of time.
- A depersonalized experience where the patient or family is treated like a number.

Identifying expectations

"No one prepared me for what this death was going to be like. Maybe they don't always know but having some ideas would really help". - Family member of ICU patient

Most families have no way of knowing what to anticipate in an ICU. Some families may have the impression that they will be able to take the patient home when in fact they will likely die. There are many variables that can influence a family's understanding, such as:

- Their expectations of what the ICU team can and cannot do.
- Their understanding of the patient's medical condition.
- What they have been told by other healthcare professionals prior to or during the admission.
- Their readiness or willingness to hear bad news.

Family members with unrealistic expectations of patient recovery may be more at risk for future difficulties, including traumatic grief.

Consider offering a pamphlet with information on what they might expect as the end of life approaches. This allows the family to read through information in their own time and ask questions when they are ready.

- *When death is near*

Encouraging questions

"I had a million questions about what was going on, but I had the feeling that I could not take up too much of a doctor's time. I was also afraid that my questions might be interpreted as being accusatory. I did not want my father's care to be compromised so I kept quiet". – Family member of ICU patient

"During rounds you are being hit with all this information at once and sometimes you need time to absorb it before coming up with questions". – Family member of ICU patient

Families may worry about getting in the way, being seen as complainers or taking too much of your time, so they may not ask you questions. You can counter this by inviting inquiries, such as: "*Please ask questions at any time. This an be a very confusing time. Part of my job is to help you understand what is happening and I'm happy to help clarify things as much as I can".* Their

questions can help you to understand where a family is at, how close they are to accepting the realities of the situation, and what they most need from you.

Daily rounds provide an excellent opportunity to build a valuable relationship. This gives you a chance to meet the family and them a chance to ask questions. Many families appreciate hearing a summary in terms they can understand. Also keep in mind that some people need time to sit with and process information before asking questions.

Answering questions

"People can deal with what they know; they have a hard time dealing with what they don't". – ICU Nurse.

"No one prepared me for what this death was going to be like. Maybe they don't always know but having some ideas would really help". - Family member of ICU patient

Start with your own questions: Ask families what they understand about the situation. You can then slowly help them connect the dots, which can help to demystify the situation.

Provide information that's clear and accurate in a way that a family can manage. Determine which and how much information the family can take in and understand.

Periods of ambiguity, such as waiting for a test result, can be very difficult for families. Very often, people will imagine worst case scenarios. Giving as much clear –but honest—information as you can will help to reduce their anxiety.

Always be realistic with families. You may hesitate to share difficult information out of fear that you'll hurt the family. Be as compassionate as possible. Although you may be the bearer of unwelcome information, you're not responsible for what has happened, and it is not always possible to prevent psychological trauma for families. This is part of acknowledging the limits of the situation and our influence over what happens.

Assessing the social situation

By learning about a family's social context—their given circumstances, history, and relationships, you'll be better able to offer support.

The unique relationship between the patient and each family member can give you an indication of how the patient's death will impact each of them. These differences influence how each family member responds to stress and grief.

Examples of factors that will negatively affect a person's bereavement include:

- A problematic relationship (e.g., one involving abuse)
- An exceptionally close or dependant relationship (e.g., a family member who doesn't know how to drive, cook a meal, or balance a chequebook).

In addition to relationships within the family, it's helpful to know something about their other relationships. Do family members have close friends, extended family, faith or other communities that can support them? Individuals who are socially isolated often fare worse in bereavement.

Evaluate family needs

Is the family in distress? Common causes for family distress include:

1. The patient was recently diagnosed with a life-threatening illness or acute health crisis or is critically injured or made a suicide attempt.
2. There has been a progression of an underlying disease.
3. The patient is unresponsive.
4. The patient has delirium.
5. The family member does not understand why the patient was admitted to ICU or has been given conflicting information.

Supporting the family

"Listen, listen, and then listen some more. You're never going to know what they need unless you listen. Sometimes people want you to sit with them and some don't. Just physically being in the room can help". - ICU Nurse

It is important to listen to the person's words as well as what is being communicated through body language and other actions. Don't hesitate to ask families for information you need to provide effective care. It is sometimes these fine details that will best guide you on how to help support the family. For example, are they from out of town? Where are they staying? Are there children involved?

Assessing and responding to psychosocial distress

"In the end, the most important things are comforting the family and meeting them where they are". – ICU Nurse

There are several strategies for responding to and supporting a family member in distress, such as:

- **Validate the family's experience and recognize their suffering.** Point out areas where the family is doing well. Recognize their expertise as family members in understanding and

caring for the patient. Normalize that what is happening in the ICU is extraordinarily difficult and demands a lot from them.

- **Make space for people's feelings.** Don't rush in too quickly to stop emotional reactions by speaking up or offering tissues to a family member. Moments of silence are sometimes needed so that families can collect their thoughts and process information.
- **Extend support and encouragement.** If a family member is crying and no one in the family offers support, you can gently and respectfully extend support and encouragement. Observe which family members appear to be struggling the most. It may be the person who appears to be the most distressed or it may be someone who is marginalized or silent.

*For additional information on the use of touch, see **A note about physical touch** in this module.*

Families who exhibit high conflict, poor unity, and limited expression of emotions may need more care and attention from you. These families also tend to fare worse in bereavement and so may benefit from receiving information about available bereavement support.

Observe also which family member appears to be struggling the most. It may be the person who appears to be the most distressed or it may be someone who is marginalized or silent.

Conversation Prompts:

- *What is the hardest part of this for you?*
- Is there anyone here people are worried about?
- *Can I put you on the spot? How are you doing?*

Assessing grief and trauma risk

"What really works is knowing the families in your care". - ICU family advisor

A timely assessment for grief and trauma risk can ensure that families receive the support and services they need, both while in your care and later on. If you and your team can develop a strong relationship with a family prior to a patient's death, this can lessen the risk of their experiencing traumatic grief; and even if a family member has serious difficulties later on, they may be more likely to seek out the services of a professional.

A simple way to begin is to ask families, "How are you managing the stress of all this"? An awareness of how people are coping can help you to identify those who may benefit from additional support. Your team can gather additional information by asking, "Are there other stresses happening in your life"? This will alert you to other sources of stress, such as divorce, job loss, or personal illness, any of which can increase someone's risk of grief and trauma.

Broken trust

"When she was admitted to the ICU, we were told by the team that they did not understand why she was transferred as she was too sick. It was so demoralizing to have this breakdown in communication and be left feeling that the transfer to ICU was for nothing". – Family member of ICU patient.

Sometimes families arrive at the ICU with their overall trust in healthcare providers already damaged. In these scenarios, you might be left in the uncomfortable position of trying to rebuild broken trust.

A relationship that starts out poorly may also be the result of information gaps. These may be the result of a miscommunication or misinterpretation between the referring team and the family. For example, the family may believe that the reason for admission to ICU was for treatment, whereas the referring team's reason may have been for end-of-life care.

Other information gaps that can diminish or destroy a family's trust include:

- Inconsistent information (e.g., conflicting messages from different healthcare professionals).
- Excessive or confusing information (e.g., use of medical jargon).
- Uncertainty regarding medical condition or prognosis.
- Miscommunication or misinterpretation (e.g., the family may be expecting curative treatment, not end of life care).

Although uncertainty regarding medical condition or prognosis is inevitable at times, if it is not properly communicated it can lead to dissonance between the family's interpretation or understanding of the situation and the clinical reality, which threatens the family's trust in you and your team. The best way to address uncertainty is to be transparent, which can also help build trust.

Family members may be more susceptible to traumatic grief if they have a persistent but inaccurate understanding–of the patient's prognosis. Therefore, when you see that family members and your team have different perspectives, spend time working toward establishing a common understanding in order to establish or re-establish trust.

Rebuilding broken trust

Offer a sincere apology for the team's role in the breakdown of communication. Other times, families will need time to recover their confidence in you and your ICU team. Often the family and the team do not share a common understanding and the task is to develop this common understanding. You can ask, what am I not understanding about your concerns or situation?

A note about physical touch

Exercise caution with respect to physical touch. It can be a source of comfort, but it also carries risks – for both you and for the patient or family member. Be aware that touch can sometimes blur professional boundaries and trigger intense emotions.

Patients and family members are vulnerable when experiencing grief and trauma. As a result, they are very dependent on you. Even if you ask permission, a person may not feel comfortable saying "no" to you.

Not everyone is comfortable with physical touch. Examples of things to keep in mind when considering physical touch include:

- If you don't know someone's personal history, you don't know what touch means to them
- Cultural norms
- Your own comfort

Rely on your observations of the patient and family, and use good clinical judgement to assess whether touching someone lightly is helpful or harmful.

Conversation Prompts:

- *Would you like to hold my hand for a moment?*
- *I'm sorry but I'm uncomfortable with hugs – my issue not yours – but a handshake would be great.*

Module 1 summary

Although not always apparent, grief and trauma are typical and common experiences for families in an ICU. Being able to recognize grief and trauma enables you to better support families and make a meaningful difference for them, both in the moment and after leaving the ICU.

This module highlighted the importance of:

- Understanding the various manifestations of grief and trauma.
- Building a solid relationship with families based on trust, reliability, and authenticity.
- Allowing families to have an active role by including them in the care plan, encouraging them to ask questions, and accompanying them through what may be the most painful period of their lives.

Families will remember even small moments when they received your care and compassion, and will draw strength from those memories during bereavement.

Module 2: Strategies for Working with Traumatic Grief

Module Introduction

"Families are suddenly put in a situation for which they have no preparation and are totally overwhelmed. It hits them all at once when a long-standing chronic illness becomes life-threatening or when a loved one falls unexpectedly at home and the injury is mortal". - ICU Nurse

Being at the bedside of a patient admitted to the ICU is a visceral experience for families. Each new family member who enters the room for the first time brings another wave of emotion.

Constructing a positive relationship with the family by supporting them in their trauma and grief can facilitate decision-making, enhance family experience, and lead to better bereavement outcomes. There are countless small interventions you can do to support families and make meaningful differences. Your relationships with families may be short-term, but your efforts can have a long-lasting impact.

By completing this chapter, you will:

- Learn ways to prepare the families for possible death and the removal of life support.
- Discover ways to minimize vicarious trauma for families when death occurs.
- Examine strategies for interacting with family members when difficulties arise.
- Explore strategies for follow-up after death.

Module 2, Chapter 1: Intervening in anticipatory grief and trauma

Introduction

"In the rush to do everything we can to save the patient from dying, we sometimes lose sight of the big picture. Sometimes the line is very thin between desperately trying to save someone and taking them off life support". - ICU Social Worker

"After you've done what you can medically to help, and the team decides there is no more to be done, it is the time for the aggressive interventions to end. There needs to be a transition from trying to save a life to 'How do we help them die well'?" – Family member of ICU Patient

Many ICU staff describe an increase in intensity around the time leading up to death, with sometimes extraordinary measures being taken to try and reverse an impending death. However, when death is inevitable, the goals of care change. These critical transitions—from cure to comfort—can sometimes be resisted for various reasons, such as:

- **Insufficient training.** Lack of focus in medical and nursing curricula on death and dying and the psychosocial skills needed to support patients and families at the end of life.
- **Reluctance to shift away from prolonging life.** Difficulty shifting away from a treatment approach. Death challenges everyone to face uncomfortable feelings, such as ambiguity, powerlessness, shame, and despair.
- **Fear of failing or abandoning the patient.** When death is likely, there can be a feeling that your team has failed or is abandoning the patient. However, there are always ways to support the suffering of a patient and family at the end of life.

In this chapter, the transition from a curative approach to an end-of-life approach will be addressed, with emphasis on working with families in anticipatory grief and traumatic distress.

Preparing families for death

"When working with families, we always try to use the most precise words possible. I'll often say that while things are looking good NOW, things remain critical and can change hour to hour. I both encourage families to be cautiously optimistic while trying to prepare them that this might not go well as any of us hope". - ICU Physician.

"Sometimes it takes families a few days to understand that we cannot reverse the medical situation and the patient will die. They may not be ready to hear that yet and may want us to try everything… Often when you show you have done all you can, it goes a long way with families". – ICU Physician

Preparing for the possibility of death

There is a subtle balance between being realistic and not taking away hope. You don't usually start by saying that death is likely; but it's good practice to start using words like 'death' and 'dying' when this is a possible outcome. By taking care to be sensitive and compassionate, you can speak about death and dying in a way that helps the family to prepare for the likelihood of death and can lead to better outcomes in bereavement and may prevent traumatization.

Preparing for the certainty of death

While you may have a clear idea of what is going to happen, the family is confronting a new and life-altering experience and struggling with feelings of grief and trauma. A few things to consider when death is certain:

- **Never make assumptions that families know that death will occur.**
- **Families may resist discontinuing active treatments**. For many people, pursuing active treatment is an expression of love and ending it represents a betrayal.

- **Families may need assistance to shift to a new reality.** This requires your clinical wisdom, patience, and ability to tolerate both anxiety and powerlessness.
- **Families may wonder what dying and death look like.** For many, the only time they have seen someone 'die' is on TV or in movies. Ask families if they want you to describe how this patient's dying and death might look (e.g., what will occur when the breathing tube is removed).
- **Different cultures have different approaches to death**. Families may have specific cultural practices or rituals related to death. Be open, respectfully curious, and willing to understand and respect their beliefs and values. Remember that some cultures believe that the afterlife is impacted by the way that the person is treated as they are dying and how the body is handled after death.
- **Who wants and needs to be there at the time of death**. Some family members will want to say goodbye before their loved one dies, whereas others may wish to not approach someone who is actively dying. Some families may also want a religious or spiritual leader to be present. Try to ensure that people who should and need to say goodbye have a chance to do so.

By preparing families, you can give them a sense of what to expect and reduce their risk of further traumatization and bereavement difficulties

To frame decision making, these conversation prompts can help bring clarity:

- *We are trying together to find the best course of action. Something that might help us to decide about this is to ask, "If the patient could see themselves right now, what do you think they would they say we should do"*?
- *Is there a religious leader or someone else from your spiritual community you'd like us to call at this time?*

Preparing the room

"On the day he was removed from life support, they moved him to a quiet room at the end of the hallway without a lot of traffic. It became a kind of sacred ground; we were given privacy, the staff was extra quiet, and they even parked a refreshment cart outside the room…I felt very respected by the treating team. At the time I was unaware of all the things the staff was doing for us but it made all the difference". - Family Member of ICU patient

Here are some other tips that can be helpful to families when preparing the patients room when death is imminent:

- **Provide a quiet, private low traffic area.** Families consistently report that being in an area with low foot traffic and less exposure to other patients and families makes a big difference at the end of life. If bed management and logistical concerns make it impossible

to move the patient to a quieter room, be straightforward with the family about this limitation and offer an apology (see conversation prompt below).

- **Reduce noise and remove unnecessary equipment as much as possible.** Families often find it easier to witness the dying process dying process if equipment around the patient is minimized such that the setting is as natural as possible.
- **Offer a "compassion cart".** It can include refreshments and snacks, which allows families to stay at the bedside.
- **Devise an "end of life" symbol to post on the patient's door.** This will let other team members know that a patient is dying (e.g., a white rose or a butterfly on the door to the patient's room) so that noise and other distractions can be kept to a minimum.

Conversation Prompt:

- *We're very sorry that we're unable to move him to a private space. We know this must be difficult for you.*

The challenges of removing life support

"Everything changed when I took the decision to withdraw life support… Taking in all the information was overwhelming; it was hard to breathe, let alone stand. But I knew that the decision we made was honouring my husband's wishes". - Family member ICU patient

"Some people just can't wrap their head around what has just happened. Those who are preoccupied with "what ifs" or "what else could have been done" go down this rabbit hole of blaming themselves and tend to struggle more". - ICU Social Worker

The decision to withdraw life support is usually an agonizing process for families. Regardless of who is making the decision, it is a heavy burden. Whenever possible, the decision should be made collaboratively among the patient, family, and your team.

After a decision has been made, family members may feel some degree of relief, coupled with guilt as to whether they made the right choice. It's often a good idea to directly ask questions about this, as families may not talk about guilt even if they experience it. You can support the family by:

- Asking how they are feeling.
- Reinforcing that everyone did their best under very strenuous circumstances.
- If appropriate, reassuring them that the decision was consistent with the patient's previously expressed wishes
- If appropriate, reassuring them that your team agrees with the decision. Reinforcing why withdrawing life support was the best course of action may be useful.

- Often the guilt families feel relates to the idea that they gave up too early. Let the family know that it is not entirely your decision or theirs, but that if you thought that they were making a bad decision, you would tell them.

Conversation Prompts:

- *How are you feeling about this? I am asking because a lot of families feel guilt. We can talk about that if you want.*
- *Based on our experience, withdrawing life support was the best and only course of action. [Patient's name] had little quality of life and wasn't going to improve. We considered every option and tried everything we could to reverse their condition. And you did the best you could too, being with them.*

Promoting family self-care

"I would occasionally leave the room and then come back after a brief walk. My family would stay in the waiting area and give me a chance to go and get a coffee. I talked to friends on the phone and that helped give me a little sense of normalcy. Listening to music also helped as it was something both my wife and I both enjoyed". – Family Member ICU of Patient

Families may need gentle prompting from you to take a break. Many people have a very hard time giving themselves permission to go home to get some sleep or to eat a good meal. You can reassure the family that the patient will be well looked after and that you will contact them if there are changes to the patient's condition. You can remind them that everyone needs some time to recover their energy to continue supporting the patient and that even a small break from ICU can help give a new perspective.

Families may be reluctant to leave the bedside for fear of missing the moment of death. Be realistic about how quickly things can change clinically. Leaving the bedside always carries some risk of not being present at the time of death, but it is not reasonable for anyone to expect someone to be at the bedside indefinitely. It is also hard to imagine that the patient would expect their loved one to do something that would compromise their own health and well-being. Ultimately, the decision is up to each family member.

*See **Chapter 2, the Moment of Death,** in this Module for more information on how to support a family member who is not present when the patient dies.*

Family members will benefit from not having to face traumatic grief alone. Very often, they will be too preoccupied or overwhelmed to reach out to friends and other family members. You can help families on the ICU to mobilize outside support by offering to contact people on their behalf.

Conversation Prompts:

- **"***I know it's hard to step away but it's important that you take a break once in a while. You need to keep up your strength, and I'm sure [patient] wouldn't want you to wear yourself out. We'll take good care of [patient] while you're gone."*
- *There's always a possibility that you might not be here at the moment of death. This could happen whether you go home to rest or if you stepped out for only a few minutes. What would it mean to you if this happened*
- *Is there anyone else in your life you'd like to have present or nearby? Can I call anyone on your behalf?*

Unfinished business

"I was really looking to heal that rift between us. The social worker helped support me through what was and what was not possible given the circumstances and the history of our relationship". - Family member of ICU patient

Unfinished emotional or relational business between a patient and their family can be complicated. Sometimes, meaningful moments of connection and healing can occur before death. However, complete resolution of all issues is impossible. Guilt and regret are very common at the end of a life.

Even practical tasks, such as conversations about DNR/goals of care, wills, deeds, or bank accounts contain an emotional element that may be triggered by old wounds or resentments.

Families may look to you for direction and guidance in managing these situations. Exercise caution whenever you begin to feel drawn into conflicts. You and your team need to exercise caution whenever you begin to feel drawn into any resulting conflicts. Remember that you're not part of the family and don't have the benefit of knowing its history. While you can offer support, be careful not to offer advice or judgments.

You may want to engage the psychosocial or spiritual care professionals in your facility. They have experience in preparing for difficult conversations around the end of life.

Conversation Prompts:

- *I understand that you've had a difficult relationship with your mother and were hoping to resolve that. That might or might not happen, are there ways you might come to terms with this?*
- *Even though other people have told you that you must forgive your father before he dies, this is really your decision. Would you like to speak with someone from our psychosocial or spiritual care team about this?*

Module 2, Chapter 2: When death occurs

Introduction

"We aren't taught in school how to deal with situations we can't fix. But I have learned with time how important the symbolic human touch can be for many people. When the patient died, the entire team was around the bedside. There was a real sense of community that I think helped everyone get through that moment". - ICU Nurse

This chapter offers suggestions for providing support to families at the moment of death, particularly where a death is traumatic. Regardless of how prepared a family is for the death, it will be an intense and difficult time. Consideration is given to whether or not family members were present, and to the difficulties many families have in leaving the room after death has occurred or their decision to not be present as the patient died. It will also be important to read family cues prior to providing support, as some families may wish to be left alone.

The moment of death

"I really appreciated the personal touches of the team, particularly when they offered their condolences, each coming to offer a handshake and say a word about how much they were sorry for my loss". - Family member of ICU patient

Your words and demeanour when notifying a family of a patient's death are extremely important, both in the moment and later in the family's bereavement. Use simple and clear language and convey sympathy and empathy. An insensitive notification of death contributes to traumatic and complicated grief.

Assess the family's needs surrounding privacy. For some, this will be a sacred, very private time. A sincere expression of condolence may be all that's needed. Silence can be very powerful and respectful; your presence can provide great comfort.

It can also be important to assess their **cultural, religious and spiritual needs.**

- Visit by spiritual or religious leader for prayers or other rituals.
- Chanting or loud wailing
- Positioning of the patient.
- Washing, dressing and shrouding of body by members of the cultural or religious group.
- Reluctance or refusal to move the body on a designated holy day or for a prescribed period time.
- Use of traditional medicines or visits from traditional healers.
- No crying over or touching the body for fear of holding the person back.

- Presence of family with the body until it's moved by the funeral director.
- Reciting creeds or reading sacred texts.

After the moment of death

"I really appreciated the personal touches of the team, particularly when they offered their condolences, each coming to offer a handshake a say a word about how much they were sorry for my loss". -Family member of ICU patient

Different ways to communicate your condolences include:

- *I'm sorry to tell you that Sam has died.* *Long silence*. *Please accept my condolences.*
- *Would you like me to stay with you or would you prefer some time alone with [name]? I can wait outside the door in case you need anything.*
- *Is there anyone you'd like me to call at this time?*

Immediately after the patient dies, remain calm, compassionate, and be a stabilizing presence for families. Offer your sincere condolences. Ensure that the family knows that care will be given to the body, according to their wishes. Many families appreciate having grief and funeral resources in the forms of pamphlets that outline various local services.

Some ICU services offer a universal prayer: a non-religious reading intended to offer a meaningful acknowledgement that the person has died and that the team was grateful for the opportunity to care for the deceased.

When a family member isn't present at the moment of death

Sometimes a family member is not present for the patient's death, and they often feel enormous guilt. Other common feelings include anger, shame, failure, and betrayal.

Acknowledge whatever feelings the person has and try to gently neutralize what has happened. Remind them that you tried your best, however unfortunately there are some things not within our control. If the person had left the patient's room for some period of time, you can provide assurances that they were well cared for and, if true, died peacefully. You can also remind the family member of all the time they spent at the bedside and how helpful that was. If the person never had a chance to be at the bedside before the death, acknowledge their efforts in trying to be there.

Conversation Prompts:

- *I know you were worried about leaving her and not being here when she died. You made the best decision you could at the time. Remember how many hours you spent with her.*

- *I know you did your very best to be present when they died. We're very sorry you weren't here, but that's not your fault. Things changed very quickly and this was unexpected. Sometimes we can't be everywhere we want or need to be.*

Minimizing vicarious trauma for families

A person doesn't have to witness an event to be affected by it. If a family member wasn't present at the moment of death, ask if they'd like to know what happened. If they agree, describe exactly what happened without being too graphic. This is an effective strategy for preventing traumatization, which can result from imagining countless terrible scenarios.

When families witness a traumatic moment of death

"I have memories of ICU seared into my mind that still cause me a lot of pain…the most traumatic part of all was seeing my mother in terrible pain". - Family member of ICU patient

People are at greater risk of experiencing trauma if a death is sudden, violent, perceived as preventable, or if the family believes the patient suffered. Some traumatic deaths are inevitable, such as from massive pulmonary embolism; others are less predictable. Sometimes, traumatization can be minimized by strongly recommending that they step outside.

Unit practices may include family presence during resuscitation. Further, some family members wish to be present at the moment of death, even in situations that may be difficult to witness (e.g., cardiac arrest). In this instance it is important to have a dedicated staff member with the family to coach and support them through what may happen and what they will see, smell, and hear

Conversation Prompts:

- *It's OK if you want to be in the room, and it's OK if you don't. I just don't want you to be surprised if he dies while you're outside the room. This could be very difficult to witness. I'm here to support you*
- *I'm sorry that you had to go through that. Sometimes things happen that we just can't predict. It's very difficult to witness. Would you like to sit somewhere quiet with me for a while?*
- *I don't want you to be alarmed by any of this. They are pushing on his chest to pump his blood throughout his body, and they are pushing oxygen into his lungs. They are also putting in a special intravenous line to give him medication to try to restart his heart. This is a normal resuscitation, and this team is well-trained to do what they're doing."*

Helping the family leave the room and the ICU

"After my mother died in the ICU, I did not want to leave". – Family Member ICU patient

It is often distressing for families to leave the room after the death. Explore with the family what their concerns are in leaving the room. Ideally, families will find a way to leave on their own terms. Some families will benefit from having the staff or close friend accompany them off the unit.

If you have concerns about a specific member of the family and how they will manage in the immediate future, you might:

- Ask how they will get home.
- Ask if anyone will be staying with them tonight.
- Ask who they can call if they need help.
- Encourage them to make an appointment with their family doctor. (You can remind them that they've been through a lot and will benefit from this follow-up.)
- Accompany them to emergency if there is any risk of imminent harm.

Module 2, Chapter 3: Problematic and critical issues

Introduction

"It was only 1 hour and 10 minutes from the time of her admission to death. Things were moving so quickly we didn't even have time to get her name. We were too busy trying to save her life". – ICU Nurse

Sometimes a family member will have an intense reaction or become immobilized as they witness and experience a traumatic ICU situation. On occasion, these reactions will require you to draw on skills that you may not use every day. These critical situations include the family member going into major distress possibly requiring professional referral or intervention; the patient experiencing quick deterioration or a long ICU admission resulting in death.

This chapter addresses some of these situations and offer suggestions on how you can respond to these challenges.

Containing major distress

"We are here to provide some stabilization for families. I will ask people to look at me, to hold and squeeze my hand. All we are doing is riding out the crisis". – ICU Spiritual Care Provider

When families are in acute psychological distress, you can create a protective holding container that helps to keep them safe. Help to ground the person by:

- Getting a cold washcloth for someone's face.
- Speaking in a calm and reassuring way.
- Sitting on the ground with the person and helping them gradually come back into the sense of their body.

Many individuals freeze or experience intense emotions when traumatized and it will take them some time to unwind from this state of hyperarousal. In almost all cases, the intense emotional moment will pass. Just be patient, present, and offer small words of support and encouragement. Try to get the family member in contact with, and surrounded by, those closest to them as quickly as possible.

When families' distress warrants professional intervention/referral

"As her husband started to deteriorate, she started coming to the unit intoxicated and threatening suicide. We had to develop a protocol in consultation with Psychiatry for how to respond... This kept her safe as well as the other patients and families". – ICU Physician

"When her mother was dying, the daughter started hallucinating and having delusions. She had magical ideas that were totally not in reality...We decided to take her down to psychiatric emergency where she was admitted". – ICU Physician

It can be challenging to judge when a family member's suffering merits a professional referral or intervention. Relying on your team's collective judgment may be helpful.

Certain behaviours are red flags that require an immediate response to ensure everyone's safety. Directly address these with the family so that you can develop and implement a workable plan. Consider a consult with your psychiatry department in developing a protocol. Situations that might require immediate response and/or referral are:

- If a family member reports life-threatening physical symptom, insist they seek immediate medical care. Some ICUs suggest attending the ER, other ICUs have made links with local family medicine clinics to provide rapid access and assessment for family members.
- If a family member displays psychotic features, such as mania or delusional thinking arrange a psychiatric consult. If you send a family member to psychiatric emergency against their will, this may result in irreparable damage to your relationship.

Highly traumatized family members may have inappropriate and atypical responses, such as rapidly oscillating between crying and laughing. Some may be confused, disoriented, and forgetful. Listening and being a stabilizing presence may be enough for a distraught family member to return to baseline. Some settings have an on-call spiritual care provider or social worker who can help contain psychosocial distress without the need for psychiatric intervention.

A period of observation may be indicated to determine if the family would benefit from a psychiatric consultation.

Rapid deterioration

"His condition went from fine to dying in seconds. The team moved in to try and stabilize him…there was just so much chaos. No one had time to review anything with me". - Family member of ICU patient

Sometimes the clinical situation moves so quickly that there is no opportunity to form any kind of meaningful relationships or even meet with the family before death occurs. In these situations, it can be very healing for families to have a thorough debriefing.

- Present information about what has happened in a simple and clear way. Leave out distressing details if possible.
- Express your condolences to the family.
- Let them know that you did everything possible.
- Ask if they have questions and take your time in answering them as honestly and compassionately as possible.
- Acknowledge any details that are unclear to you.

Assuming a humble and respectful position can help families to accept some of the ambiguity.

Conversation Prompts:

- *We did our absolute best. It was unclear until almost the very end whether or not he would survive. We didn't want to give up our efforts to save him until we had exhausted all the options. I'm very sorry for your loss.*
- *We don't know everything that happened, but we will try to get you as much information as we can. We understand that not having all the answers is very difficult. We can tell you what we are aware of. This is what we know….*

Long-term admissions that end in death

A relatively small number of ICU admissions are long-term and can last for months or even years, with many ups and downs, before ending in death. Bonds between you and a family can become deeper, with a great deal of mutual trust and respect. Often, all parties are more vulnerable when these relationships end.

There are ways that you can honour both your team and the family so that everyone is better prepared to move forward in their grief. A family may choose to host a small gathering to thank the team for their dedicated service. Many families value sharing and hearing stories of the

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patient's time on the unit. Your team may wish to pay special homage to the patient at or after the time of death, perhaps gathering together and visiting the patient's room together.

Module 2, Chapter 4: Strategies for follow-up

Introduction

Most ICUs have no formal bereavement follow-up programs. This may be changing as many families report a need for bereavement support specific to ICU deaths and some staff express interest in offering aftercare support.

The following sections outline a few strategies that you may be able to implement in your ICU setting.

When families come back to the unit

"When you leave the ICU, it does feel as if you can never call them again. I would have appreciated a follow-up of some kind, maybe having the team say, 'It's our practice to give you a call in a month or so after the death in case you want to come back and ask questions or talk'…". – Family member of ICU patient

"It was very useful for us to go back and have a follow-up meeting, revisit my time in ICU, and retell the story with someone who was well informed about the case and answered my preoccupying questions". - Family member of ICU patient

Families will occasionally find their way back to the ICU. Coming back to the place where someone died might be part of their healing process. It takes great courage to return to places associated with profound trauma and grief. When a family returns to the ICU, do your best to make them feel welcome. A heavy workload may limit your time with families. This can be difficult for both parties. Remember that even a quick hello followed by an apology that you are simply too busy to talk can go a long way with families.

Conversation prompts:

- *It is good to see you. Many people find it very difficult to return to the ICU. Please accept our condolences again. We have been wondering how you have been doing.*
- *I'm sorry I can't stay and talk, I would really like that. Unfortunately, I have patients that need to be seen. Please accept my condolences.*

Post-death family meetings

A positive and constructive family meeting before death can make an enormous difference for families experiencing psychological trauma and can help them better cope with their bereavement. Families report great appreciation for the chance to ask questions of the team as they try to make sense of their experience and rebuild their lives. Unsurprisingly, many have expressed the wish for a similar meeting after death has occurred.

Purpose of a post-death family meetings

It's important to determine why a family is seeking a meeting. It may be helpful to ask the family in advance of the meeting if they could indicate what they would want to talk about, or send a list of specific questions (if applicable) to help staff prepare answers. The following are some typical reasons:

- To get some kind of "closure", whatever that may mean to them.
- To try to make sense of what happened (e.g., getting answers to pre-occupying questions about a particular event).
- To express appreciation to the team.
- To repair a relational rupture with the team that occurred while the patient was on the ICU.
- To express anger and dissatisfaction.

If the main purpose of the meeting is to register a complaint about the care provided to the deceased, it would be best to meet in conjunction with a representative from patient relations or management. It may be almost impossible to explore grief and provide support in a meeting with this focus.

Planning and conducting good family meeting

Remember that you have a lot power in establishing a good atmosphere for this meeting. Below are some general recommendations on how to structure and conduct these meetings:

- Find a suitable environment to conduct the meeting that is quiet, with places to sit and with tissues and water on hand.
- Gather the most involved care team members at the meeting.
- Welcome the family back and offer condolences. *"I'm sorry we are meeting under these circumstances".*
- Allow the family to set the agenda by saying, *"We have X amount of time to spend together. How would you like to use that time?"* We recommend that you plan no more than one hour for the meeting.

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- If possible/applicable, encourage family to share their questions and concerns with a member of the ICU team before the meeting in order to help the team prepare/best address their concerns.
- Try to start with medical topics. Psychosocial issues are better addressed in the latter half of the meeting because they are more sensitive and easier to talk about.
- Sometimes families will have very specific medical questions that can be answered straightforwardly. There may also be existential questions that can't be answered. You can acknowledge that these are unanswerable.
- Families may want to be reassured that everything was done to prevent the patient from suffering (or dying).
- Families may need to hear that the right end-of-life choices were made.
- Families often appreciate the opportunity to express their emotions.
- Your team can assess how the family is coping with their grief and trauma, offering a referral to local resources as needed.
- Before concluding the meeting, take a few moments to assess the impact. Ensure that everyone feels they have a clear understanding. Don't end abruptly or fail to address all the items on the agenda, as agreed upon at the outset. A poor ending to a family meeting can undermine the good work you've done.

Responding to anger, criticism, or complaints

Occasionally, a family will be angry or question medical decisions. Whether or not you think there are any grounds for this, it's important that you make a sincere effort to listen. Remember that they are vulnerable in their grief and are trying their best to make sense of their experience.

Do your best to avoid entering into a power struggle or an *us versus them* dynamic. By listening, you'll be showing a willingness to explore their perspective with them, to "stand in their shoes" for a while.

Depending on the situation, it may be good for you to offer a simple apology, such as "we are very sorry this happened to you". This often has the effect of shifting the conversation so that you can move forward.

If necessary, be gentle but firm in setting boundaries. Maintaining a good boundary with a family in conflict will help them feel safe and help keep things contained. Do you best to keep a calm composure.

Remain calm in the face of aggression but make clear that it's not acceptable. If the family member remains dissatisfied with your responses, you can refer them to the Office of the Ombudsman of the hospital if it seems appropriate.

Other follow-up considerations

Relatively few ICUs have memorial services in place to recognize those who have died under their care. Usually, these memorials cover a certain timeframe, such as all the deaths that occurred within the last few months, and families of the deceased are invited to participate and staff are welcome to attend. These memorials are non-denominational and secular in nature to ensure accessibility. The goal is to provide an opportunity for the community to gather, recognize the important deaths, and to offer support and appreciation to all stakeholders. You and your team, in whole or in part, may wish to develop ways to acknowledge your grief while also honouring the important you work you do.

Module 2 summary

Supporting family members during times of acute distress, such as when a patient is dying or has died presents you with many challenges. Developing strategies to manage these situations is important not only in the moment but also in the future when, for example, families who are not realistic or prepared for death tend to have more difficulties coping in the future.
Some of the key topics discussed in this module included:

- Navigating the moments of transition when life-saving interventions shift to end-of-life measures, which is likely to be one of your biggest challenges.
- Finding ways to be as realistic as possible with families, who may be struggling to make sense of what is happening or accept that the patient's death is inevitable.
- Identifying ways to manage critical situations and constructively responding to exceptionally difficult situations (e.g., comforting a family member who was not present at the moment of death).
- Employing frequent and transparent communication, which can help prepare families for what is coming.
- Recognizing that returning to the ICU may be how some families cope with their grief and trauma, and making them feel welcome (e.g., if possible, make time to check in with them, see how they are doing, and answer any questions that they may have).

Module 3: Supporting Children Visiting the ICU

Introduction

This module addresses the complexities of bringing children, age four through adolescence, to the ICU. It also provides guidance to make the experience as constructive as possible. The strategies can be used in family meetings as well as less formal interactions.

Always try to secure parental agreement for carrying out any of these suggested intervention/strategies.

All children are unique. This information is meant to serve as a guide and is not meant to replace professional support.

By completing this chapter, you will:

- Understand why families may or may not wish for children to visit a patient in the ICU.
- Learn common concerns and questions children often have and how to address these.
- Explore ways to facilitate and ease a child's visit and prevent trauma and future difficulties with grief.
- Learn ways to support a child when death occurs.

For a more detailed treatment of supporting children in grief, please see www.kidsgrief.ca

Notes about language:
"Parent" is used to refer to anyone who has direct legal responsibility for the daily wellbeing of a child. That could include other family members, guardians, foster parents and others. References to "primary caregiver" in videos refer to all of these individuals. **"Children"** is used to refer to all children up to the age of minority.

Module 3, Chapter 1: Should children visit the ICU?

Helping families decide whether to bring a child to the ICU

For parents, it can be very difficult to decide if they should bring a child to the ICU. Many families will turn to you when looking for answers to the question, "Should I bring my child to the ICU"?

How children may feel about being included:

- Respected, valued, and cared for.
- Some sense of control and predictability in a situation that is beyond their control.
- Relieved when some of their worries are addressed and misconceptions are clarified.

- Reassurance that the person is being well cared for in the ICU.
- A chance to have meaningful time with their family and the patient.

Common impacts of not bringing children to the bedside include:

- *Increasing anxiety and ambiguity:* Children will fill in the blanks with their own ideas and imagine the worst. "It must be really bad if they think it'd be too scary for me".
- *Feeling helpless:* Children often have things they would like to do, say, or bring for the person in the hospital; or they may simply want to spend time with them.
- *Feeling isolated:* Children may feel they're not seen as being important enough to be included. They may worry that the person doesn't want to see them. This may increase their feelings of being alone and missing the person.
- *Discouraging open communication:* When children feel that some things are being kept from them, they may behave similarly and start keeping their thoughts or feelings from others.

You can also help support parents when children don't want to visit. A visit to the ICU should never be forced. Alternatively, children can stay connected through phone calls, sending art and letters, or being in the building but not coming into the patient's room.

<u>Why families may not want children to visit</u>

There may be times families may think it is best for the child not to visit the patient. Some of these reasons may include:

1. The child may be currently coping with another serious trauma (perhaps they recently lost another parent or family member).
2. They may be visually hypersensitive and seeing the patient in ICU may traumatize them.
3. The patient themselves may request that the child not visit them at this stage.

As previously mentioned, children can still stay connected with the patient through the phone, face time etc. without physically visiting the patient in ICU.

It is important to respect the family's and the patient's decision whether it is to allow or not allow the child to visit the patient.

Preparing instead of protecting

Help parents prepare their children for what they might see, hear, smell, or feel at the hospital. While ICU equipment, tubes and masks are part of your work life, it is new and often scary to children.

It can help to suggest parents take a photo of the patient connected to medical equipment and show this to the child prior to their visit. They will know what to expect and are less likely to be surprised or overwhelmed. Invite children to ask questions about anything they see in the photo, and describe the equipment such as an IV, oxygen mask, ventilator, and any other tubing or medical devices, and explain what each device does. Be aware that beeping monitors or IVs, ventilators, call bells, and any other sounds can be frightening when they are unfamiliar. Unusual smells related to the person's bodily functions or cleaning products can also be jarring and distracting. Talking about these unfamiliar stimuli helps to reduce children's fears.

Responding to questions

"When she was at home my mom said I gave her a headache when I was too loud. What if I make too much noise in her room; will I hurt her even more"? - 8-year-old

Responding to children's questions honestly and in a way that they understand will lessen their anxiety and build trust that they are valued and will be included.

"Can I catch it?"
Explain that injuries and dying aren't contagious. When the illness isn't contagious, reassure the child that they can't catch it. Name the illness and explain that people don't catch it like a cold or flu. If the illness is contagious, let them know how it is spread and what precautions are being taken.

"Did I cause it?"
Let the child know that the illness or injury wasn't caused by something they did or didn't do or say, their thoughts or feelings. In the case of illness, reassure them that although we still don't know exactly why some people get sick and others don't, we do know that the child is not to blame.

"Can I/you cure it?"
Reassure children that there are people all over the world trying to find ways to cure different illnesses and injuries, but that this illness or injury is too strong for any medicine that has been found. Assure them that it is not their responsibility to try to cure the disease.

"What if I hurt them?"
Reassure them that nothing they do will make the person die faster. Show them how to navigate the medical equipment and what they can and can't touch so that they can be close to or touch the person without disturbing their care.

"What if I don't know what to say or do?"

This question is common for kids and adults. Reassure the child that it's alright not to know what to say or do. Make a list together of things they could say, such as, "I miss you," or "I'm glad I got to see you".

You can suggest different ways a child can interact with the patient. Depending on their age, they can:

- Bring something from home to show or to give to the patient.
- Bring a favourite stuffed animal or comfort object with them.
- Choose music.
- Hold hands.
- Talk about their day.
- Do activities like homework, colouring, or video games.
- Paint fingers and toenails.
- Apply moisturizer to arms and legs.

If the relationship is physically close, consider helping the child or youth maintain that closeness as much as the dying person is able. For example, encourage the child to sit quietly close to the patient while patient rests their hand (or strokes) child's head, hand or arm; encourage child to link fingers with patient's hand or if the child is small (and the patient able), allow child to take a short rest next to the patient.

Module 3, Chapter 2: Preparing children to enter the ICU

The meaning of ICU admission

Begin by getting a sense of what they understand of the situation. Their answers will tell you how comfortable they are talking about it, what they have heard and interpreted, and what they are focusing on. Listen carefully to the words they choose; if they use any medical words or euphemisms, ask what those words mean to them. Build on and clarify their responses. Try to use clear, simple and concrete language to explain any concepts that they don't fully understand.

Conversation Prompts:

- *What do you know about this hospital and/or the Intensive Care Unit?*
- *What can you tell me about why [patient] is here?*
- *What does 'life support' mean?*
- *You said, 'passing away'; what does that mean?*
- *Sometimes when people have trouble breathing, we put a tube in their throat to help them.*

Explore previous hospital experiences

Children may have had earlier hospital experiences - positive or negative - that inform their current visit to the ICU. By asking questions about the past, you can clarify the present. Even if a child has no hospital experience, they may have formed inaccurate impressions based on what family or friends have told them or on what they have witnessed on television or in movies.

Explaining the impact of the illness or injury

When children hear words like *sick*, *ill,* or *injured*, they sometimes think that this is the same as an everyday cold or injury. This can lead to their worrying that other illnesses or injuries will lead to hospitalization. For this reason, it's important to use the words *cancer, car accident,* or *heart attack.* This helps even the youngest children understand that these are different from a cold, flu, or everyday injury. It also gives children a name for the changes they are seeing in the patient and decreases the chance of misunderstandings.

Use clear language to explain how the illness or injury is affecting the person physically, cognitively and behaviourally. If the illness or injury is affecting the person's thoughts and behaviours, let the child know this.

Conversation Prompt:

- *Your aunt has an illness and it's causing her body to not work properly*
- *Your grandfather hit his head very hard when he fell, and it hurt his brain. Since our brains control our body's movements, he is having trouble talking and moving his body the way he wants to. He may not be able to show that he hears or recognizes you, but it will still be comforting for him to have you there.*

Explaining dying and death

Young children may struggle to understand some of the abstract aspects of dying and death, such as causality and finality. To help them learn and understand, use clear, concrete language. Explain that "dead" means that a person's heart stops beating, their lungs stop breathing, and their brain stops working so that they don't think, hear, see, smell, or feel pain anymore.

Let them know that the person who is ill or injured isn't dying because they didn't "fight hard enough" or "try hard enough" to stay alive.

Clarify that even though the person will not "get better" or recover from the illness or injury, the team is working to help them "feel better" or more comfortable.

Sometimes children worry that talking about dying makes it more likely that the person will die. Reassure them that this isn't so.

Conversation Prompts:

- *Your uncle has a lot of cancer in his body, which is causing his body to not work properly. The cancer is stronger than all of the medicines that can be used to try to get rid of it. Eventually his body will stop working, and his body will die. When the body dies, it never works again.*
- *Even though your brother has tried really hard to stay with you and your family, his injuries are just too serious for his body to be able to keep working. That means that he will die. It's not his fault, and if he could change things, he would.*
- *Your dad is getting medicine through his IV – the tube that goes into a vein in his arm. It cannot make his disease go away, but it is taking care of the pain in his head and his body*

Module 3, Chapter 3: The visit

Visiting rules

It helps children to know how they're expected to behave when spending time with someone who is dying. Let them know what they can do, such as touch or talk to the person. Explain what they can't do and why – especially if it's something they're used to doing, like jumping into a lap. Some children mistakenly think the person will die sooner if they do something wrong. Let them know if:

- The room needs to be quiet.
- There's equipment they shouldn't touch.
- They need to behave differently than usual when they are with the person who is ill.

When children first arrive

When children first arrive and before entering the patient's room, if time permits, give them a tour, including the nursing station, bathrooms, kitchen, and family room. Point out and explain different signs (e.g., isolation precautions). Preparing the child can help them feel comfortable during their visit and minimize the initial shock and possible negative reactions when they first see their loved one.

Conversation Prompt

- *While we are walking, do you notice anything you have questions about?*

Entering the patient's room

Before entering the room, do a final check-in to see if the child or youth have additional questions or worries. Encourage parents to create ways for the child to signal that they need a break (e.g., a prearranged signal such as an ear tug can). The usual guidelines are to have the child accompanied by someone they trust and feel safe with.

How children may react

Children may have a wide range of reactions, such as being:

- On-edge
- Sad or fearful
- Quiet or withdrawn
- Clingy or anxious
- Giddy or energetic

These are all natural reactions.

When children experience intense emotions

Children may express intense, unfamiliar, or uncomfortable emotions in ways that vary from adult reactions. Young children and teenagers are usually working hard to manage feelings which are often very strong and unpredictable. Model being calm and patient while reassuring them that all feelings – as well as crying – are okay.

When the patient is agitated, aggressive, delirious, or in pain

"There is no clear line about what's too much for a child to experience. It's about matching the support and the resources with how difficult the situation is and the unique qualities of the child, rather than prematurely concluding this is too difficult". – Child life specialist

If the patient is highly irritable, floridly delirious, or otherwise overcome by pain, decisions about visiting should be made based on the preferences of the child and their parent(s), and your team's clinical judgement and experience. Discuss with the family if having the child witness certain events might be overwhelming. One way to proceed is to ask the parent(s) if they think their child would be able to deal with what is happening in the patient's room, and whether they or other supportive adults will be able to debrief and support the child afterwards.

Regardless of the decision, it's important that you explain to the child how the illness, injury, medication, or dying process can mix up a person's thoughts, feelings, and behaviours. This will help to clarify that the patient's actions do not reflect how they feel about the child.

You may also want to explore ways that children or youth can engage with the patient under these circumstances. Some options include:

- Engaging through a window.
- Communicating by phone.
- Sending something into the room with someone else.
- Having a brief visit at the bedside that includes an exit strategy.

If the child wants to have a visit, explain that you will do your best but if the patient is too sick or too upset, the family will have to stop and try again another day.

When the child is present at the moment of death

When death is near, tell the child that you think the person's body is about to stop working. If they want to stay, let them know what to expect (e.g., how the person's breathing might sound). Tell them how the team will respond.

What if the death is likely to be, or becomes, traumatic?

Whether or not the child was present at the moment of death, explain to them afterwards what happened in clear and simple terms but avoid gruesome details. Explain that the person no longer needs all of the medical equipment, so it will be removed. Remind the child that the person no longer feels anything.

If CPR or other extraordinary measures are taken, have the family bring the child to a quiet spot to wait and let them know they can come back later. Witnessing a death where there is excessive pain or suffering (e.g., choking or aggressive medical interventions, will most likely be traumatic for a child, as well as for many adults.

When the child doesn't want to leave the patient

A child may have many reasons for why they don't want to leave the bedside. If the patient is still alive, they may worry that the patient will die before they are able to visit again. In these situations, talk with the child or parent about when they can visit again and ways they can stay connected (e.g., phone or video calls).

If death has occurred, the child may worry about the patient being left alone or about what will happen to them afterwards. They may also wonder if the patient is "really dead" or if they might wake up again. Remind them that when a person dies, they don't wake up and their body doesn't feel pain, cold, hunger, etc., so they won't need the same things as they used to. Let the child know who will "take care of" the patient's body after they leave.

Preparing for the possibility that it's the last visit

It's not always possible to know which visit will be the last. If death is close, let children know that this may be their last chance to be with the person while they are alive. This gives them the chance to say goodbye if they want to or just spend time with the patient. This can be a very powerful moment for everyone, with a lot of deep feelings expressed. Allow children all the time they need for this final separation.

Some other ways for a child to bring about a meaningful conclusion to the visit include:

- Giving the patient a hug or a kiss.
- Taking a photo of holding their hands.
- Singing a song or saying a prayer.
- Leaving something that they brought, or a drew or wrote while there.
- Tracing the patient's hand on a piece of paper or fabric.

Regardless of what is done or said, some children (like adults) will not feel "ready" to leave the patient. Especially when the patient has died, it's preferable for children to find a way to separate from the patient's body on their own terms.

Conversation Prompts:

- *Some people wish they could stay with their person forever. It's okay to feel that way. It's hard but they try to find different ways to feel close to the person. [Pause] It's almost time for you to go. How can I help you to walk away when it's time? Would you like to hold my hand and we can walk away together? Would you like me to count to 10? Would you like to take 3 deep breaths and then go?*
- *In case [patient] does die, is there something you'd like to do or say before you leave today?*

Module 3 summary

Children have important questions, worries, and needs for support when a family member is in the ICU. Parents and caregivers may be reluctant to bring children into the ICU, wishing to protect them from what they imagine would be "too scary". Unfortunately, this leaves them alone with their fears and difficult feelings, compounding their grief experiences.
Some of children's most common concerns include:

- Worrying about whether the illness or injury is their fault.
- Wondering if it is contagious or curable.
- Fretting about how they can help the patient.
- Worrying about who will look after them if or when the patient dies.
- Wanting to visit the patient but feeling nervous that they might accidentally harm them.

- Feeling unsure about how to interact or what to do in light of the patient's abilities.

You are uniquely positioned to talk with parents about how to best prepare, support, and include their children, and can share specific strategies for doing this before and during a visit to the ICU. These interventions can be extremely helpful to children, as well as for the dying patient and family members, contributing to more positive experiences and grief-related outcomes.

Module 4: Responding Constructively to Work-related Vicarious Trauma

"People who work in ICU can absorb a lot of trauma, and this is both a good and a bad thing. But there is no doubt that the intensity of ICU can weigh you down sometimes and we can never predict how it will impact us or how we will react". - ICU Nurse

Introduction

As someone who works in an ICU, you likely feel a great sense of pride in your work. Part of this stems from being part of a highly specialized team that saves lives. Most likely, you derive immense personal meaning from your work.

Along with the rewards of your work, there are also costs. The ICU has been described as a place where you're working "at the threshold", suggesting that everyone has their limits. You are a human being before all else and at some point, you may discover that either your body or your psyche cannot sustain high levels of stress indefinitely.

Clinicians and professionals who work in ICU often experience *vicarious trauma,* (also called compassion distress and secondary traumatic stress) referring to the psychological impact of exposure to trauma in the course of one's professional practice. Given the intensity and the life and death experiences of your everyday work, the potential for vicarious trauma is enhanced.

Is this you?

If you can relate to the questions below, you may be feeling the effects of vicarious trauma.
Do you…
Feel significant regret about decisions about medical interventions (undertaken or not)?
Feel excessively angry, frustrated or upset when interventions don't have the desired result?
Feel preoccupied that you or the team could have or should have done more?
Feel an especially close bond to the patient or family?

By completing this chapter, you will:

- Learn the symptoms of vicarious trauma.
- Discover ways in which grief and trauma can impact you.
- Identify clinical situations in the ICU that could lead to vicarious trauma.
- Understand how to work with your vulnerabilities.
- Establish constructive responses to work related grief and trauma.

Module 4, Chapter 1: Vicarious trauma & moral distress in the ICU

Introduction

"Ten years ago, the implicit policy in ICU was to keep things to yourself and say, 'It is just part of the job'. Now it seems more acceptable to be vulnerable. Because of the burnout and staff distress, we are more attuned to the pressures of the work". - ICU Physician

Vicarious trauma can take a physical, mental, spiritual, and emotional toll on people who experience it. A concurrent phenomenon which both similar and dissimilar features is work-related grief which occurs in response to patient death. The impact of patient death on health care providers is well established. The nature of your relationship to the family and patient, the way in which you personally identify with a loss, and the extent to which your grief goes unacknowledged can all result in work-related grief.

With your ongoing exposure to grief as a professional working in ICU, the potential risk for you to experience vicarious trauma is greatly enhanced.
In this chapter we will explore vicarious trauma in detail including what it is, it's potential impact, why it is generally *not* discussed in the ICU and how you may also experience moral distress while working in ICU.

Understanding vicarious trauma

Vicarious trauma refers to the impact of working with and being exposed indirectly to psychological trauma, most commonly experienced by professionals. It is also sometimes described as *secondary traumatic stress* or *compassion distress*.

Vicarious trauma can take a physical, mental, spiritual, and emotional toll on people who experience it. Common symptoms include:

- Chronic physical and emotional exhaustion
- Depersonalization
- Irritability
- Feelings of self-contempt
- Difficulty sleeping
- Weight loss
- Headaches
- Poor job satisfaction

Why is vicarious trauma not talked about in ICU?

"There is a sense of stigma attached to words like grief and trauma, a desire by staff not to have these labels put on them". - ICU Spiritual Care Provider

ICU staff commonly report that grief and trauma tend not to be part of their everyday clinical vocabulary.

Often staff avoid discussing the impact of intense ICU experiences on own feelings and reactions. You may avoid discussing your experiences for various reasons:

- Minimizing the impact of grief and trauma can be a form of self-protection from other uncomfortable feelings, such as shame or weakness.,
- Worry about being judged by your colleagues.

Like many strategies, minimizing (e.g., downplaying the significance of a traumatic event) and denial have a positive or constructive aspect. During difficult moments, it may serve you well to push aside your feelings of grief or trauma; but trying to keep your feelings "underground" over long periods of time will lead to future difficulties.

Short-term coping strategies tend to be not sustainable, and you may find yourself shutting down emotionally in other parts of your life. You need to develop other strategies that can serve you in the longer term.

Moral distress: Disagreement with the plan of care

"It can happen that the team isn't in agreement with the family's goals of care. It takes a lot of communication and checking in with the team. It can lead to situations where the nurses or respiratory therapists are administering interventions that they perceive are furthering a patient's suffering with no sizable benefits or purpose". -ICU Physician

In addition to being more susceptible to vicarious trauma, ICU clinicians can be more likely to experience moral distress.

Moral distress occurs when someone perceives a moral conflicting dilemma and feels a responsibility to act (or not act) but cannot due to personal, cultural, or institutional constraints. Dilemmas that provoke moral distress are almost inevitable in a complex clinical setting like the ICU.

When a staff member indicates that they are in moral distress based on the treatment plan, your team needs to come together to discuss and revisit the treatment plan. Otherwise, this moral

distress can spill over into interactions with the family and undermine the ability to provide effective care as well as lead to staff burnout.

How disagreement among the team affects the family

When the family receives conflicting or inaccurate information, it undermines their confidence in your team and can contribute to a poor bereavement outcome.

Module 4, Chapter 2: Where are you vulnerable?

Introduction

"'Ten years ago, the implicit policy in ICU was to keep things to yourself and say, 'It is just part of the job'. Now it seems more acceptable to be vulnerable. Because of the burnout and staff distress, we are more attuned to the pressures of the work". - ICU Physician

How you define "being well" is unique to you. You will likely have some indications in yourself if you're struggling emotionally at work. If you are unaware or are avoiding the impact of vicarious trauma, your ability to care for patients, families, and yourself will be diminished. Awareness is key to developing strategies that work for you.

In this chapter we will examine various situations that can arise while you are working in ICU that can expose you to greater risk of experiencing vicarious trauma. You will also be introduced to some common responses to vicarious trauma as well as some characteristics, triggers and questions that will help you to identify your own susceptibility to vicarious trauma.

When you go too far with life-saving interventions

"Aiming for life at all costs is a problem because it sometimes leads to no quality of life. We must ask the question, 'What is an acceptable way for the person to live?' This is certainly true for the patient, but we also have to consider how the family will live when this is all over... and maybe how the ICU team will too". - ICU Physician

Families often want you to do everything you can to save a patient, which can put a lot of pressure on the clinical team. At some point it may become clear that further intervention compromises the patient's quality of life to a significant degree. The question then becomes, "*When is enough, enough*"?

Maintaining your sense of realistic limits is important. When death is certain, your team will recommend to the family that you adopt a plan of care focused on comfort. If you and your team don't have a well-defined boundary of when to shift from curative care to comfort care or your

team and the family is not in agreement with switching the goal of care, your vulnerability to vicarious trauma increases.

Just as families are more at risk if they are not prepared for the possibility of death, so too are you if you lose sight of the "big picture". Research on death anxiety clearly suggests that not acknowledging our own fears of death can lead to more aggressive treatments and may ultimately put us at risk of more profound vicarious trauma.

When your anxiety management no longer works

"Intensive care is very intense". – ICU Nurse

Anxiety is a daily part of ICU work and as previously mentioned, can lead to **vicarious trauma**. As humans, we have protective mechanisms that may or may not serve us well when responding to anxiety.

When faced with vicarious trauma, you may adopt some common responses, two of which are avoidance and over-compensation. You may avoid patients or family members; or you may adopt a kind of "controlling mode" whereby you become fixated on medical details that are no longer particularly useful or start to over-manage a family by, for example, ordering them around.

These two responses can gradually undermine the effectiveness of the care you provide and your relationship with the family. Acknowledging your feelings of anxiety and stress can help you start to identify alternative ways of coping. This can be challenging but can make a big difference to your well-being. Some questions to ask yourself to determine the impact of your feelings are:

- What is my fear/anxiety making me do at work?
- What is my fear/anxiety keeping me from doing at work?

Poor outcome? When a situation goes badly

"It is hard to avoid a sense of personal failure and shame when we are not able to save a patient. It is especially hard when the family is upset with your services. It is in these moments that you find the team somewhat traumatized". - ICU Physician

There will always be situations you can't fix such as when pain that can't be controlled or when death that can't be avoided. The more invested you are in controlling an outcome (e.g., "*None of my patients will die*"), the more negatively you'll be impacted when that doesn't happen, even if for reasons beyond your control.

Working in the highly stressful ICU environment means that at some point there will be missteps. You may feel responsible for a poor outcome or a family member may blame you, resulting in feelings of guilt and shame.

Guilt refers to the feeling felt when one has done something 'wrong' (perceived or real). What one perceives as wrong is often related to their moral code. **Shame** refers to a self-conscious emotion in which one feels unworthy, bad or wrong due to a shortcoming, an act or omission of an act (perceived or real).

Working in the highly stressful ICU environment means that at some point there will be missteps. You may feel responsible for a poor outcome or a family member may blame you for it. There's a place for *reasonable guilt*, which encourages accountability for your actions. There may be lessons to be learned that can inform and improve your future practice. To benefit in this way, you need to allow yourself time to reflect on how you'd approach a similar situation differently, both professionally and personally.

There is also *exaggerated guilt*. With reflection, you can see that it's pervasive and not realistic. You may feel guilty about events beyond your control, and this can keep you caught in the past as you repeatedly replay a certain event in your mind. This loop can prevent you from looking at what's underneath (which is likely anxiety) and can serve to shield you from acknowledging how frightening and beyond your control ICU work can sometimes be.

Feelings of guilt or failure, or of letting someone down, can be very troubling and may add to your grief response. If you're struggling with these feelings, consider discussing the case with a colleague or asking for a case review.

When you over-identify with the situation or a person

"The same week my mother had a heart attack, I was back at work and a patient I admitted had a cardiac event. My patient was going through the same thing my mom was. I had a hard time putting it aside". – ICU Nurse

Sometimes the line between your life inside and outside of ICU blurs. Quite often, overidentification with a clinical situation happens at a subconscious level and you may not recognize it immediately.

To become more aware of how your beliefs and experiences might impact how you care for patients and their families, reflect on:

- How do I feel about death?
- What are my own experiences with grief and trauma?

- How am I seeing this family? What am I not seeing?
- What assumptions am I making about this family member that might not be true?
- How can I best understand and work with my own response to help the patient and family?

Although over-identifying can be harmful/painful, your experiences can also give you insight into the experiences of the families you're working with. As a result, you may develop deeper connection and empathy and be better attuned to their needs.

When you disconnect too much

"We are trained to disconnect at work. The problem is that we risk being separated from our own emotional awareness and ultimately staying detached from others. We aren't teaching clinicians how to reconnect". -ICU Spiritual Care Provider

Disengagement is a way people cope with trauma and grief. Sometimes disconnection will manifest in depersonalization and derealization.

You may find yourself trying to put distance between yourself, the events surrounding you, and your response to vicarious trauma. Over time, this can result in symptoms of trauma, which can become more acute if not attended to, such as:

- Intrusive memories
- Efforts to avoid certain thoughts or reminders of events at work
- Difficulties with memory, irritability, and depressed mood

Should a combination of these symptoms be occurring that are impairing your ability to function either personally or professionally, it may be an indication of Post-Traumatic Stress Disorder (PTSD). PTSD is a diagnosable, clinically significant, and treatable psychological condition that merits a professional consultation.

Overall, vicarious trauma saps your energy and may make it impossible for you to sustain your best efforts and intentions, both at work and in your personal life. Attending to the emotions that come with vicarious trauma is necessary and takes great effort, especially because you will likely need to confront feelings of shame. Reframing these moments as opportunities to reconnect and re-engage with yourself and your life can help you grow both professionally and personally.

Module 4, Chapter 3: Working with your vulnerabilities

Introduction

"If I could tell ICU clinicians one thing that helps families, it would be to just be human and not hide behind a professional façade." - Family member of ICU patient

In this chapter you will be introduced to ways of working with your vulnerabilities around the grief and trauma you may experience, ways to maintain healthy boundaries in the ICU setting and some additional support strategies you can implement.

Working with our vulnerabilities

"It really helps when someone says that they tried their best and that they are sorry for the outcome. There needs to be more compassion in intensive care". - Family member of ICU patient

Many clinicians wonder if they should show emotion in their interactions with patients and families. Some worry that expressing emotion will impact their ability to function at a high level of competence or erode the confidence a family has in them.

The answer may be on a case-by-case basis that relies heavily on clinical judgment. Clinicians will need to maintain some sense of distance while remaining empathetic and connected. In this way, the occasional and genuine emotion (such as shedding a tear) may help build trust as opposed to prevent it. Anecdotally, families usually appreciate that the death meant something to the team as well.

Attending to the emotions that come with vicarious trauma is necessary and takes effort. It can be easy for clinicians to enter a cycle of blaming themselves for not having what it takes to do their job when the symptoms of vicarious trauma arise. Instead of entering a cycle of self-doubt, focus your energies on the suggestions below:

- Talking about feelings with a trusted person and/or a mental health professional
- Learning more about vicarious trauma and how it affects people
- Identifying problematic coping strategies that we have automatically adopted that no longer work for us
- Making a commitment to regular exercise
- Eating a healthy diet
- Getting restful sleep
- Developing hobbies outside of work
- Reaching out to family, friends, support groups and networks

The importance of clear boundaries

Boundaries are the physical and emotional limits that exist between you and your patient and families. Boundaries are essential because they establish and maintain a trusting, professional relationship and can help prevent compassion distress. In determining and maintaining your personal boundaries, you will want to ensure you preserve a balance without being too rigid but also not too fluid. If boundaries are too rigid, you may seem uncaring and detached. If boundaries are too fluid, you may have difficulty separating yourself from the situation, which can interfere with your doing your job well.

Key boundaries in ICU

Boundaries you may encounter while working in ICU include:

1. Patient is dying or has died: You may be inclined to be more lenient or accept certain behaviours, or to act in certain ways you otherwise might not (e.g., not setting limits with a family member who is verbally abusive or threatening).
2. A close bond with the family: A deeper relationship between you and the family than is the norm may develop.
3. Difficulty say goodbye: Family members may have difficulty saying goodbye or may wish to continue to have a relationship with you after the death. You may even have similar feelings yourself and find yourself conflicted between the natural pull you feel towards the family and the boundaries your training prescribes.

In these circumstances, you may feel uncomfortable about these feelings or the tension they create, and you may want to dismiss or minimize them. Find a way to set boundaries while respectfully acknowledging the intimacy, which is real and yet specific to the particular circumstances.

Reflective exercise

These are questions to ask yourself if you're facing a boundary dilemma:

- *Am I behaving differently than I would in any other call?*
- *If I'm going the extra mile for a patient or family, is it in their and my best interest?*

In the midst of intensity and time constraints in ICU, you may have little or no time to consider the finer points of professional boundaries.

Reflective exercise

The following questions may help guide you BEFORE you're confronted with boundary issues in working with patients and families in the ICU:

- *How far am I willing to go for a family?*

- *What are the boundaries that define my personal and professional comfort?*
- *When do I know my boundaries are being crossed?*
- *What would I have to say no to?*
- *What would be a situation where I could not say no and what would be the justifiable reason (e.g. the psychosocial needs are urgent)?*

Other support strategies

"We have a very tight team. It helps us get through the difficult times. I see it when we surround the patient and family at the time of death. I see it when we have our informal and spontaneous debriefings". – ICU Nurse

Professional responsibility requires that you develop personally effective strategies to manage the effects of vicarious trauma. Find out what supports your facility offers (e.g., EAPs, extended insurance coverage). Some hospitals have instituted a *Code Lavender Program* designed to support staff in times of extreme stress.
Support can take many forms, such as:

- Periodic debriefings with colleagues. (Some ICUs are moving toward instituting more formal debriefings for staff, facilitated by a third party with ICU expertise.)
- Mentoring / clinical supervision.
- Implementing a routine to unwind after a shift.
- Engaging in wellness initiatives both at and outside work.
- Creating a work-life balance that allows you to feel professionally and personally fulfilled.
- Engaging in personal counseling psychotherapy.

Module 4 summary

Exposure to grief and trauma within an ICU is ongoing, but the effects are often invisible and not discussed. A culture of suppressing the natural and common pressures of ICU often serves to protect you but can, over time, have negative consequences. Although sometimes uncomfortable, it's important for you to discover new ways to manage the day-to-day demands of functioning at the threshold between life and death. You can start by:

- Understanding where you are vulnerable and how this might be impacting your interactions with patients and families and, consequently, your professional abilities. Some clues might be overidentifying with a family, feeling unrealistically guilty or responsible for an outcome, or experiencing symptoms of burnout.
- Understanding the impact that grief and trauma has on you. If you can't see its impact on you, it's likely be hard to recognize it in others.

The ability to disconnect from your work is an important part of finding a good work-life balance; however, it is not healthy to completely ignore unpleasant experiences. Finding ways to meaningfully engage with the stresses of your work can help protect you over the long term as you develop new ways to cope and can also replenish your motivation for ICU work, adding to your satisfaction and sense of fulfilment.

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