Maintaining Emotional Balance in an Unbalancing Time

Responding to hard questions and emotional distress about COVID-19 from dialysis patients or their families





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Approaches to communication and responding to emotion



Acknowledge and respond to anxiety and fear

Recognize the dialysis center as important source of stability and routine

Honor the memory of patients who have died

3 Strategies for responding to anxiety and fear



Connect and invite response



Acknowledge emotion



Remind about resilience

Connect and Invite



Connect by inviting patients to share their concerns about COVID-19. Sometimes patients don't like to admit they are upset and they shut down.

Words that show you care about their feelings:

- Invite: "I'd like to hear what's on your mind about COVID-19."
- Check in: "Some patients have shared that COVID-19 really scares them.
 How are you feeling about it?"

Acknowledge emotion



DO: Acknowledge and empathize with emotion

Use empathic statements that accept difficult emotion

 "Sounds like you have been fearful about what might happen to you and your family.
 There is a lot that is unknown right now and everything is changing very fast."

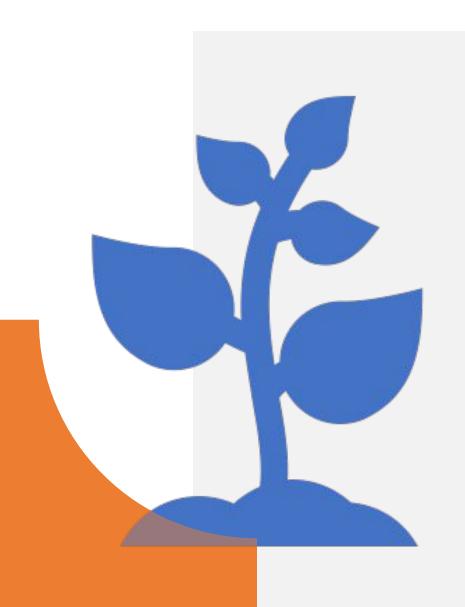
Foster resilience



DO: Foster resilience

Remind patients of their resilience and successful coping strategies:

• "What has helped you get through difficult times before?"



Resilience – Additional Resource

Excellent summary of evidence-based tips for resilience:

A psychologist's science-based tips for emotional resilience during the coronavirus crisis

Dialysis center as source of stability



Most people are comforted by the routine and the familiar.



The larger context is extreme disruptions at home - children or grandchildren staying home from school, adults telecommuting to jobs, or wage earners who lost their jobs.



The regularity of coming to dialysis, seeing familiar staff and patients, can be a very important source of stability.

Maintain routine – prepare for disruption

Maintain routine when possible

If consistent with infection control procedures:

- Do your best to maintain usual schedule.
- Let patients use their own chairs if possible.

Prepare for changes

• Prepare patients for the fact that some things aren't going to be normal.

"We all do better when we know what to expect. Things are changing all around us. We'll do all that we can to provide a sense of routine. Keeping a routine is our priority. If things need to change, we'll tell you why." Honor the memory of any patients who die



It is comforting to know you will be remembered



Rituals help us remember and cope with loss

Acknowledge and honor the memory of those who have died



Not acknowledging a loss can make it harder

- Our first instinct might be to downplay attention to any patients who might die during this pandemic. We don't want to frighten patients or dwell on difficult topics.
- But a "conspiracy of silence" leaves people alone and lonely with their questions, concerns, and grief.

People are ALREADY thinking about the person who has died

- The reality is that people are already aware of the heightened risk of death.
- If a person who has been sitting in the next station on the same shift for the past three years is suddenly absent, the patients around them are going to wonder what happened, even if they don't ask.

Patients fear being forgotten



Patients fear being forgotten

• One of the major fears and stressors for many patients about dying is that they will be forgotten.

Respectful remembrances can comfort the living

- Memorials and respectful remembrances of patients who have died can be a source of comfort.
- Open acknowledgement of another patient's death gives the message that we are remembering our patients and cherishing their memories.

Words for telling patients that another patient has died

"We are like family here. I have some difficult news to share. Given how much I care about each of you, I wanted to tell you myself. Unfortunately, Ms. S. has died."

{Pause -- let person respond.}
Name emotion they show.

"This is heartbreaking for me. It's okay to be really upset or even angry. We're here to support you and to listen. We may not know the answers, but we're in this together."

Words for responding if a patient's family member has died

"I heard this morning about {USE FIRST NAME}."

If you can remember anything about the caregiver state it. For instance:

"Linda always had the most cheerful smile."

"I always could tell that James loved you."

"We are going to miss the way Thomas always joked with us."

{Pause -- let person respond.} Name emotion they show. "This is so heartbreaking and a great loss for you to bear."

Let them know that you can tolerate the emotion.

"Something like this can make a person so overwhelmed, angry and devastated. You are safe to talk about any of that with me."

The importance of your presence

When dealing with death, your presence is far more important than the precise words you choose.

Most practitioners struggle to sit with a patient in grief, which can be very lonely when patients are left alone.

The most important thing you can do is to <u>sit with</u> <u>patients</u> in their time of greatest pain and hold that pain with them. You don't need to say much. "I am here for you" is enough.

Do's and Don'ts when discussing death of a patient or family member

Don't

- Do not attempt to fix.
- Do not discourage emotion.
- Do not try to persuade a different point of view.
- Do not get distracted during conversation (don't look at phone, computer, etc.).

Do

- REFLECT back and NAME the emotion.
- Let them know that you can tolerate their difficult emotions by holding back your own responses.
- Be present.
- A moment of shared quiet can build connection.
- When it is time to say something: "Take your time. I am here"

Some practices that other health care providers have used



Place a flower on the chair or bed of a patient who has died and leave it unoccupied for a period. For facilities at capacity, place flower on a shelf or table.



Display a *in memoriam* bulletin board with notices of the person's obituary, notes from staff, and possibly notes from family members, being mindful of patient privacy.



Displaying a ritual memory object can help with closure for all. A wreath where a memory ribbon is tied or a fountain where a beautiful stone is placed are ways to memorialize each death.



Send a bereavement card to family from the dialysis center staff.

More resources for communicating about difficult subjects

Vital Talk has posted **COVID-ready communication skills: A playbook of VitalTalk Tips**

- This is excellent. Gives you the words to say in very difficult situations.
- https://docs.google.com/document/d/1uSh0FeYdkGgHsZqem552iC0 KmXlgaGKohl7SoeY2UXQ/edit

Social Work Hospice and Palliative Care Network (SWHPN) has posted Working with families facing undesired outcomes during the COVID_19 crisis

• https://swhpn.memberclicks.net/assets/01%20Working%20With%20 Families%20Undesired%20Outcomes%20COVID19.pdf

Resources about palliative care during epidemic/crisis:

- A Field Manual for Palliative Care in Humanitarian Crises: https://global.oup.com/academic/product/a-field-manual-for-palliative-care-in-humanitarian-crises-9780190066529?cc=us&lang=en&
 - Chapter 2: Palliative Care Needs of People Affected by Natural Hazards, Political or Ethnic Conflict, Epidemics of Life-Threatening Infections, and Other Humanitarian Crises: https://oxfordmedicine.com/view/10.1093/med/97801900665
 29.001.0001/med-9780190066529-chapter-2

Let us know what other communication and emotional dilemmas you are facing during COVID-19 Pandemic

Call 202.994.7969, Email kidneycoalition@gwu.edu, Tweet @kidneycoalition



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