# ADC –March 7, 2021

## How grief and depression intersect and diverge: Helping your ESRD patients navigate emotional distress

Melissa McCool, LCSW

# Grief + depression questions:

- *What is commonly known and unknown?*
- *What do depression and grief look like in clinical practice? How are they different?*
- *Does grief lead to depression?*
- *What is the most important clinical task with each?*
- *Can they co-exist?*
- *Can treating grief prevent depression?*

# Case #1- George

- Pleasant, man in his early 60's.
- PHQ score= 12
- On dialysis for five years.
- No history of depression
- He is suddenly more withdrawn, angry, not sleeping well, isolated, negative.
- Planning to go on a long vacation with his wife.

***To be continued…*

# Case #2- Lois

- Woman in early 30's. Refuses to do PHQ.
- New to dialysis. Living in a SNF
- History of depression. Bilateral amputee
- Comes to dialysis in her nursing home gown. Doesn't engage with anyone beyond what is required. Sleeps during treatment. Doesn't volunteer information about herself.

***To be continued…*

# Case #3- Jose

- Man in his late 40's. PHQ score= 0
- On dialysis for three years. Works full-time
- History of anxiety. Waiting for a transplant.
- Patient seems to function well at home and in life. RN requested SW to see patient for depression because he started crying when the topic of transplant came up.

***To be continued…*

# Depression

20-30% of patients with ESRD are depressed [9,10]

- Increased Morbidity and Mortality

  -26.5% of depressed patients have a two-fold increased risk of death and hospitalization [11,12]

- Decreased Quality of Life

  -as evidenced by decreased KDQ scores on MCS and PCS (somatic complaints), [13]

# Depression

Common understanding:

- Disease
- Solved by medication [1]
- Genetic

Not commonly understood:

- Impact on the processing of emotions

# Grief

Common understanding: Caused by death of loved one. Experienced as five, neat and tidy stages:

1. Denial
2. Bargaining
3. Depression
4. Anger
5. Acceptance

# Grief

Not commonly understood: Any perceived loss can trigger the grief process. 11 different types:

- Complicated
- Disenfranchised
- Anticipatory
- Masked
- Traumatic
- Inhibited
- Secondary
- Cumulative
- Absent
- Collective
- Prolonged

# Disenfranchised grief

*“Grief that a persons experiences when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned.”* [3]

# KDRL -> Depression?

In psychodynamic literature, depression has been associated with a loss of some kind. [7, 8]

- "KDRL (Kidney Disease Related Loss) as a strong contributor to depression is consistent with the previous theories that loss is a significant cause of depression.
- Dialysis patients who grieve a range of losses suffer increased depression and reduced quality of life (QoL)" [2]

# Most commonly cited losses:

- Travel: 18.56%
- Leisure activities: 12.06%
- Physical functioning: 10.90%
- Work: 9.74%
- Relationships: 6.50%
- Freedom-*perception of being free from constraints*: 4.87%
- Social life: 4.87%

# Depression or grief?

## Similarities

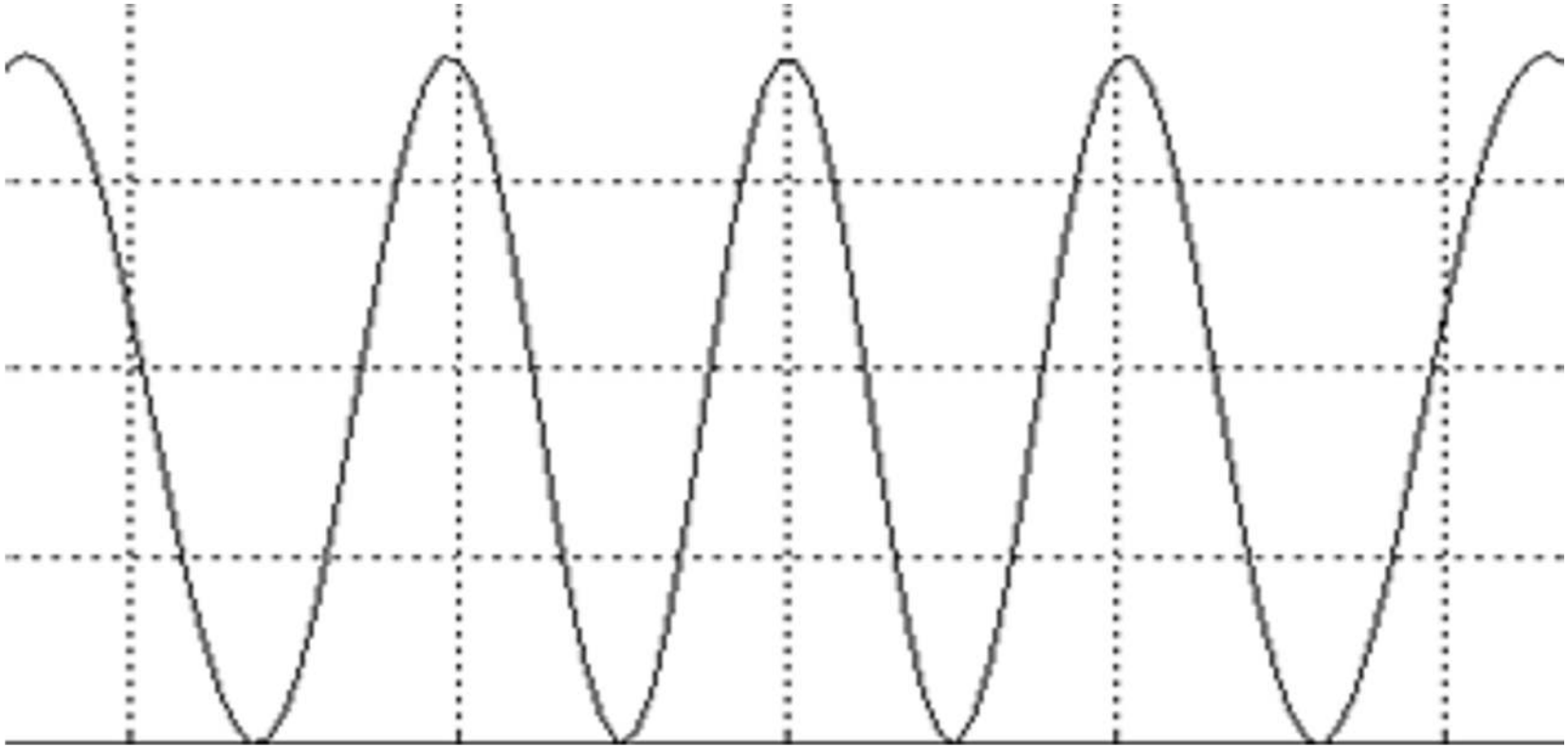
| Depression and Grief |
| --- |
| Sadness |
| Appetite and weight changes |
| Sleep problems--insomnia |
| Cognition: memory, concentration |

# Depression or grief?

## Differences:

| Depression | Grief |
|---|---|
| Overall avoidance and isolation | Specific avoidance |
| Consistent low mood | Mood goes up and down |
| Difficult feeling “blah” | Pangs of intense emotions |
| Apathy | Yearning |
| Doesn’t do many daily activities | Continues daily activities generally |
| Worthlessness | No decrease in self-confidence |
| Guilt | Occasional specific guilt re: loss |

# Difference: process

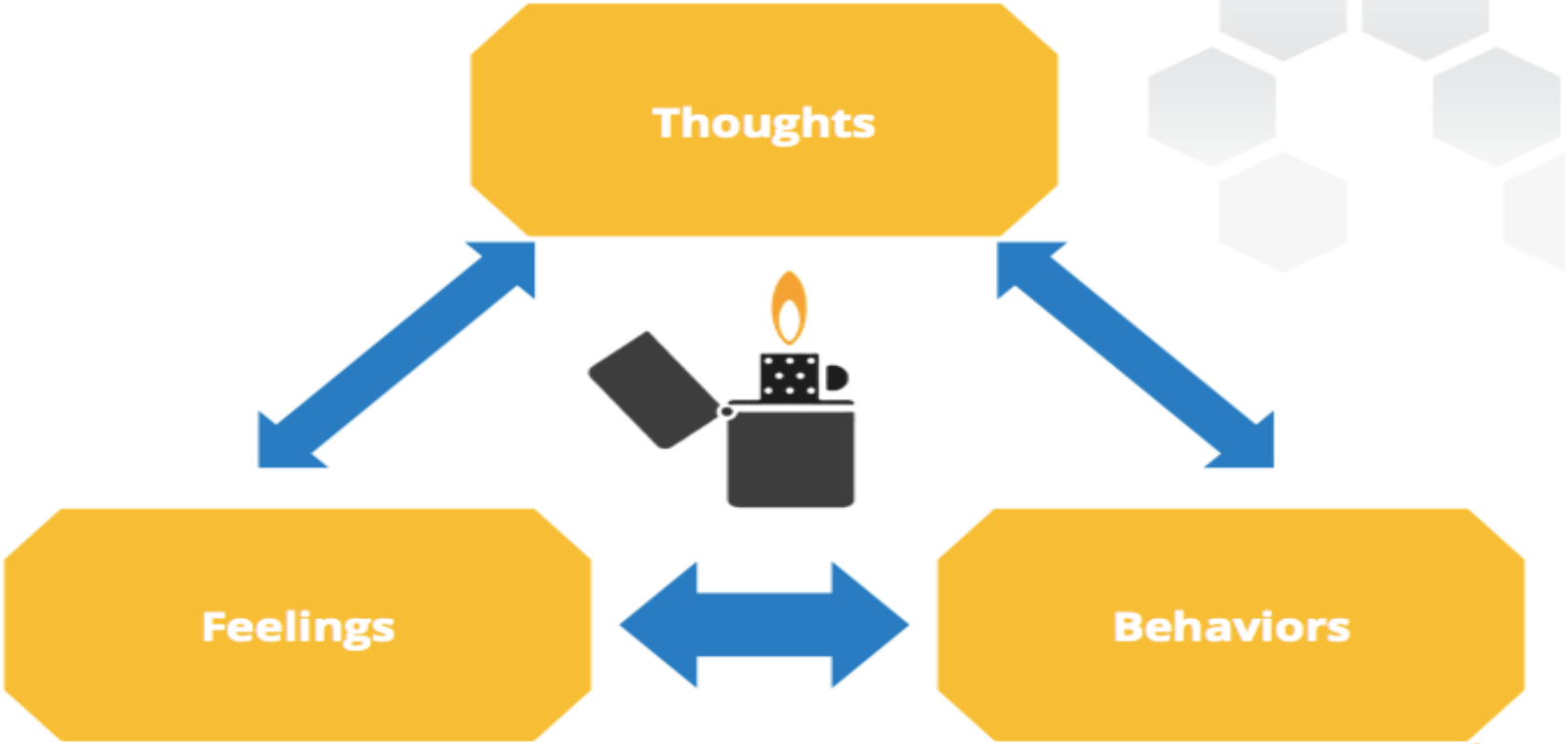


# Case #2 *(continued)*

*Woman in early 30's. Refused PHQ. New to dialysis. Living in a SNF. History of depression. Bilateral amputee. Comes to dialysis in her nursing home gown. Doesn't engage with anyone beyond what is required. Sleeps during treatment. Doesn't volunteer information about herself.*

- This patient was shut down all the time.
- There were seemingly no fluctuations in her mood.
- She was negative, isolated, and ruminative.

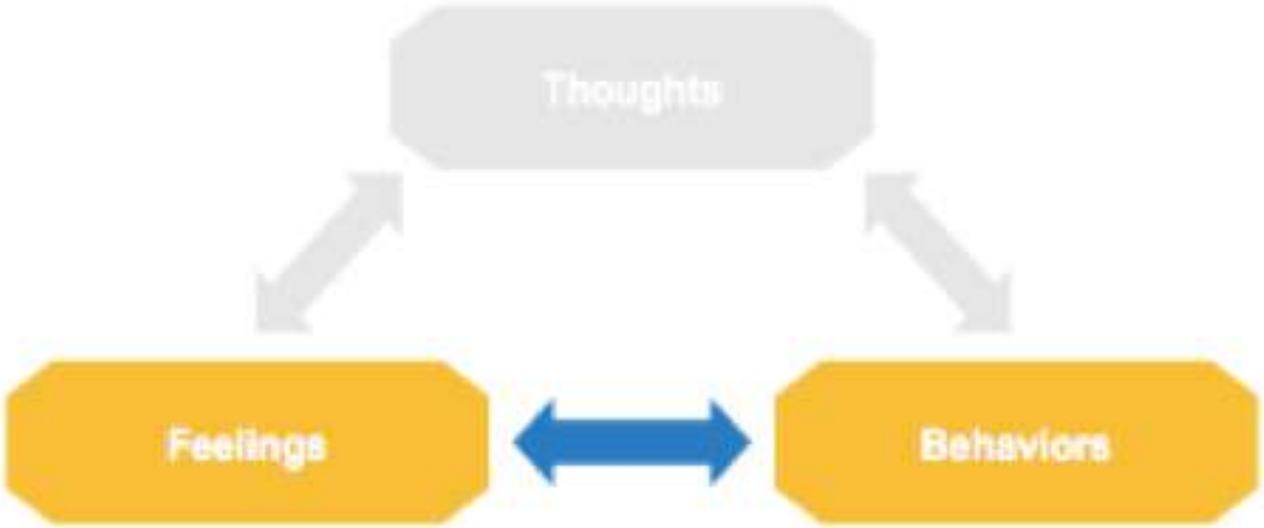
# Depression dynamic



# Thoughts are the problem

# Depression

## Main task = Decrease rumination



# Lois *(continued)*

*Woman in early 30's. Refused PHQ. New to dialysis. Living in a SNF. History of depression. Bilateral amputee. Comes to dialysis in her nursing home gown. Doesn't engage with anyone*

Talked to MD who started zoloft

- Showed her triangle. Created behavioral activation program with opposite action to lower rumination

Result--One week later:

Came to clinic a week later in clothes and with make-up. Became the SNF "It girl"

# George *(continued)*

*Pleasant, man in his early 60's. PHQ score= 12. On dialysis for five years. No history of depression. Suddenly more sad, irritable, not sleeping or eating well. Planning vacation.*

- In weekly rounds, I asked about his upcoming trip.
- His mood noticeably changed. He talked about his disappointment at having to arrange all of his treatments while on vacation. He hadn't taken any trips since being on dialysis.
- Planning his trip had re-triggered the grief process

# Is grief complicating things?

Ask about their story:

What happened? How did they lose kidney function?

- Expected or not?
- What is their understanding? how and why it happened?
- Do they blame anyone?
- How do they feel about it?

**Normalize grief process***: "Other people have found…"*

# Grief
## Main task =Affect regulation skills

Grief overwhelms emotion regulation capacity

- Escape with avoidance; “postpone” emotions until there is a “better time”

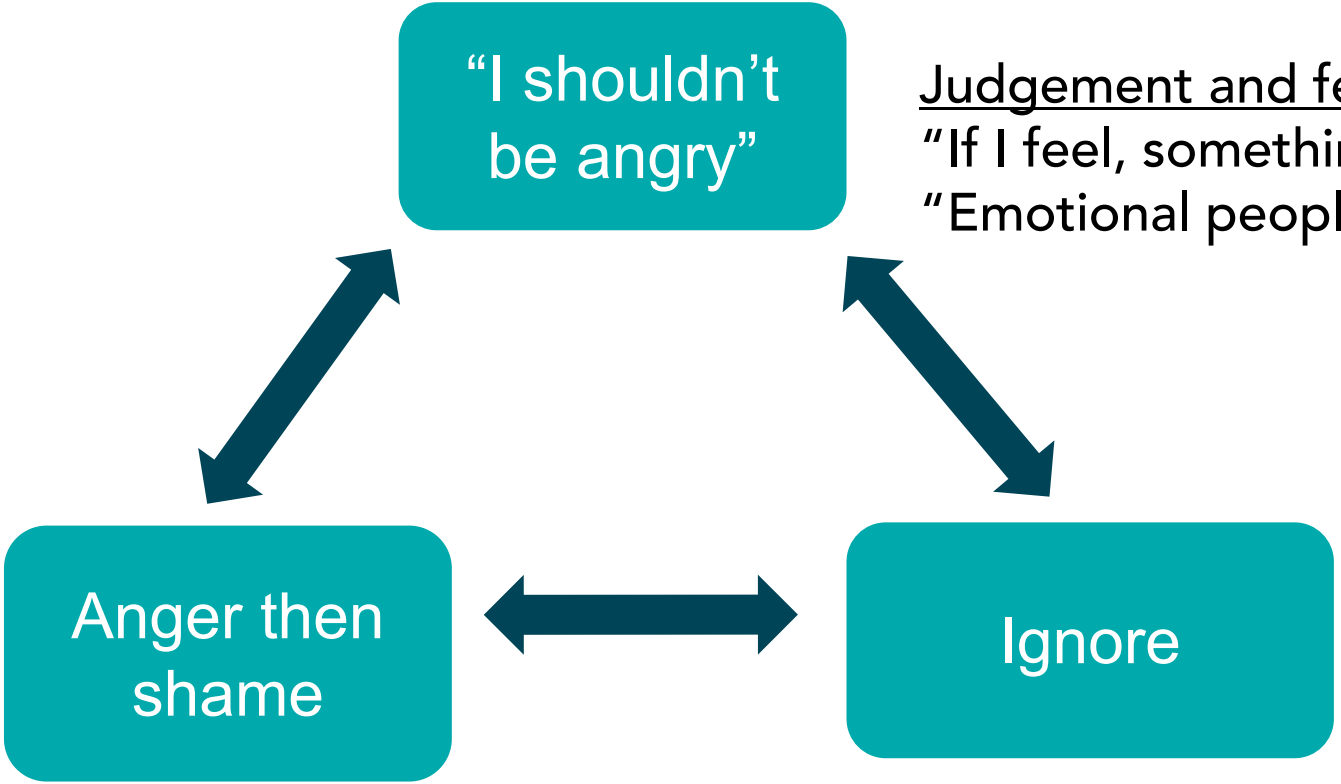
- Numbing behaviors

# Process

Bowlby

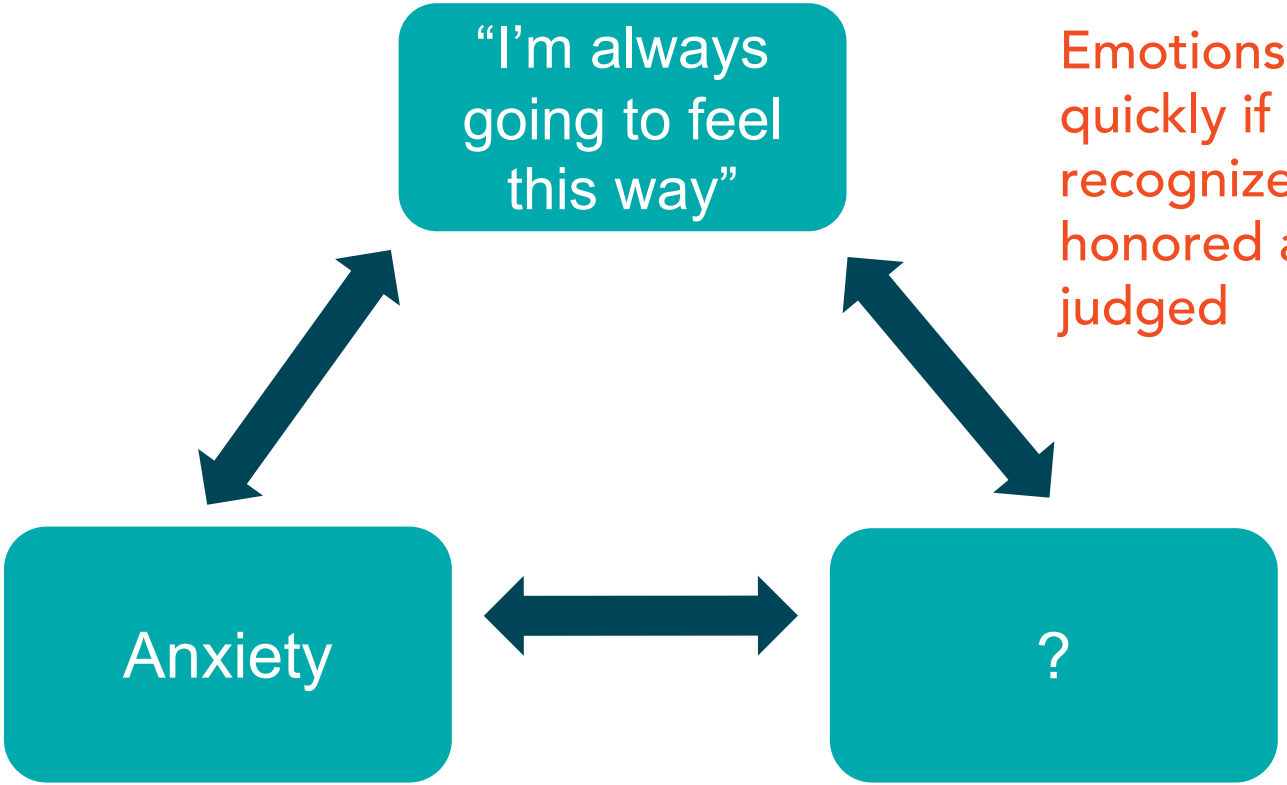
- Emotion regulation happens gradually; takes our minds time to adapt.
- Our defenses protect us from feeling the emotional pain all the time.
- Confront - avoid

# Problem: We apply logic to emotions



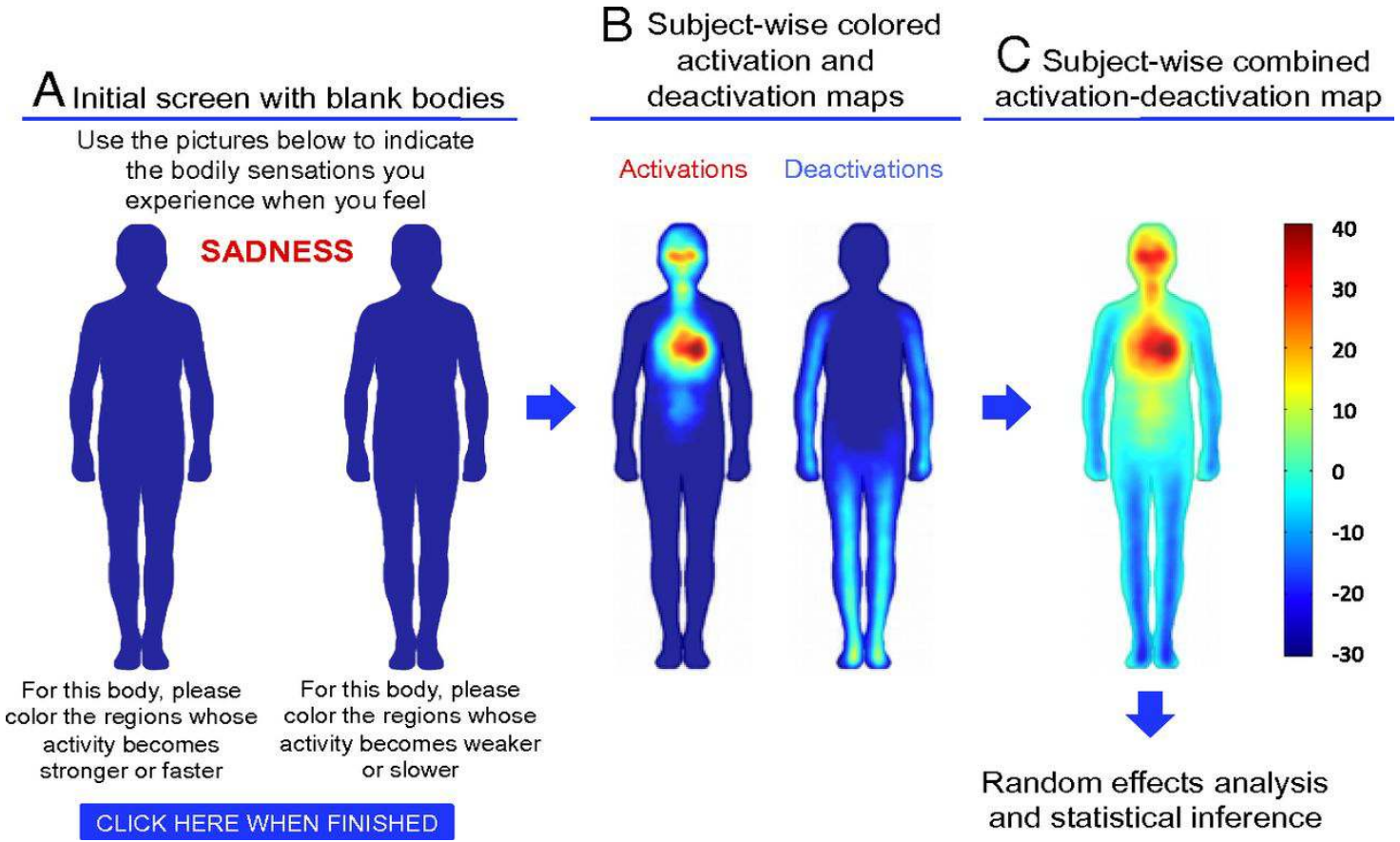

Judgement and fear:
"If I feel, something bad will happen."
"Emotional people are out of control"

# Problem: No understanding of process

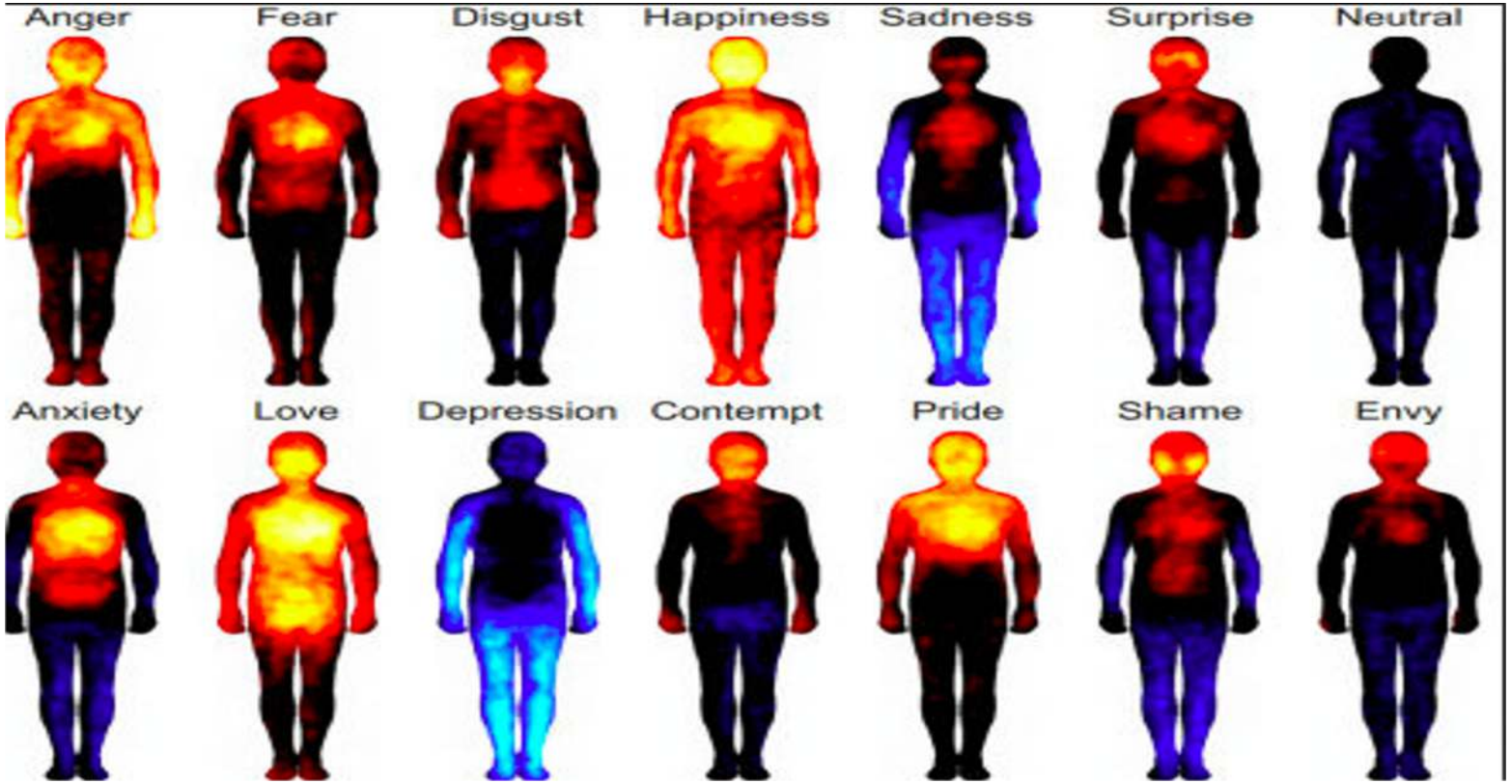



Emotions pass quickly if recognized honored and not judged

# Emotions felt in the body -4



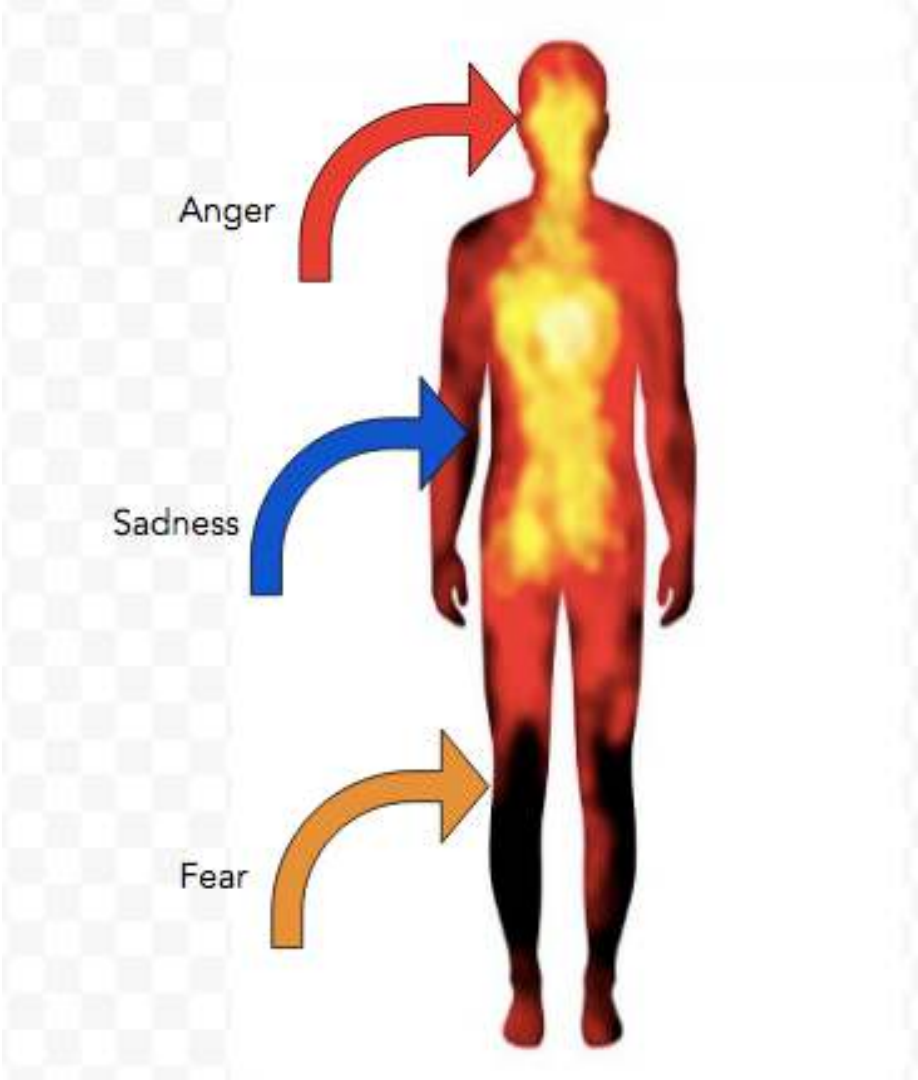
# Must exit the body



# Input--no output

Emotions get

stored in the body



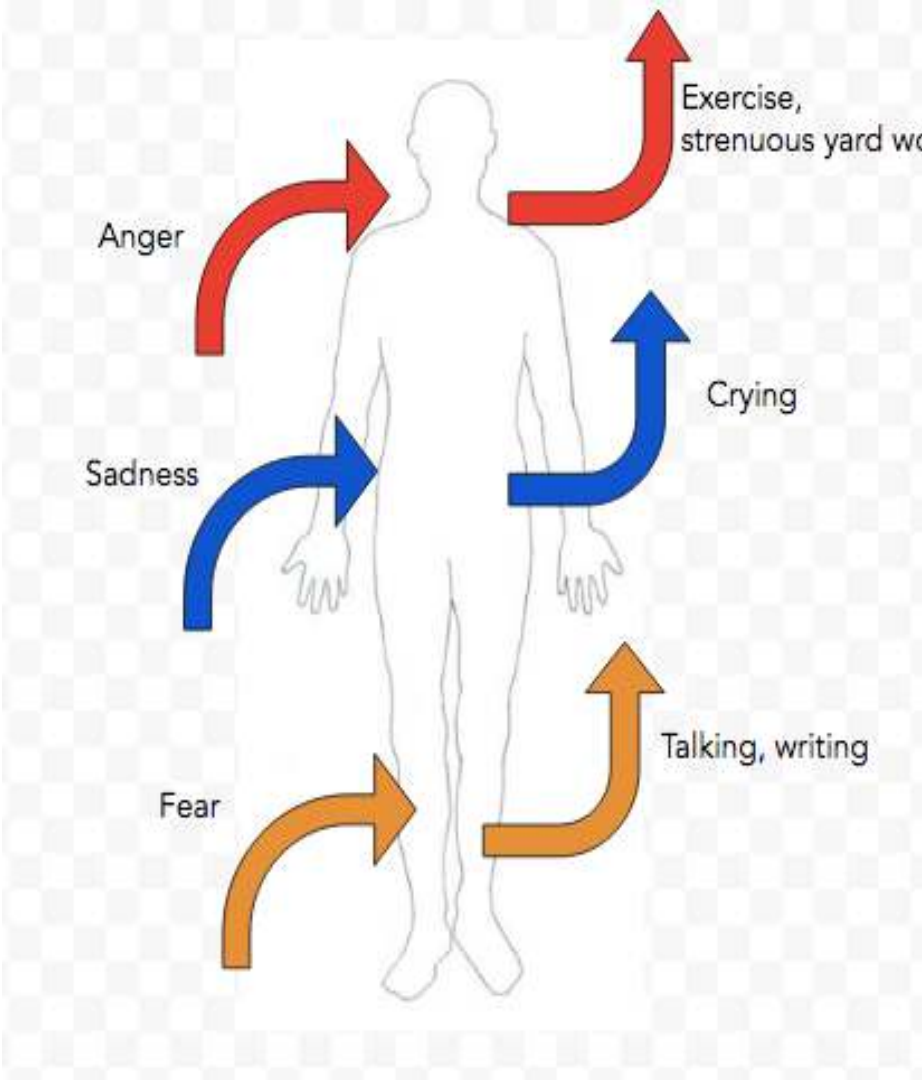
# Processing emotion: inputs, outputs

## Often there is input, no output

| Trigger --Input | No output |
|---|---|
| Sadness | Ignore, don't recognize |
| Anger | Yell, feel bad, suppress |
| Fear | Don't recognize |
| Shame | Don't recognize |

# Input and output

Emotions flow through the body, no trace.



# Processing emotions safely-6

1. Acknowledge without judgement
2. Feel *(process or touch)*
3. Release

*Simply acknowledging the emotion without judgement decreases the level of intensity*

# Ideal: There is flow

## Input then output

| Trigger → Input | Output |
|---|---|
| Sadness | Acknowledge, don't judge, cry |
| Anger | Acknowledge, don't judge, exercise |
| Fear | Acknowledge, don't judge, talk |
| Shame | Acknowledge, don't judge, write |

# Case #1- George

*Pleasant, man in his early 60's. PHQ score= 12. On dialysis for five years. No history of depression. Suddenly more withdrawn, angry, not sleeping well, isolated, negative. Planning vacation.*

- Refused medication
- Asked about his story
- Normalized his response
- Education on grief process and emotions
- Encouraged talking and writing

# Crying: Nature's secret elixir

Crying is like vomiting when there is food poisoning. Your body is trying to help you.[5]

People are scared to cry. Many negative beliefs about crying (not just men):

- *"I won't stop"*
- *"It means something is wrong with me"*

"Safe crying" goal: Give education, permission, guidance

# Case #3- Jose

*Man in his late 40's. PHQ score= 0 On dialysis for three years. Works full-time. Doing well at home and at work. RN requested SW to see patient for depression because he started crying when the topic of transplant came up.*

- Assessed patient for depression. Asked about his feelings about transplant.
- Excited but sad to leave clinic community since he has many friends. **Anticipatory grief**
- Education on benefits of crying. Educated RN on healthy processing of emotions.

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presented by the Karl Nolph, MD, Division of Nephrology

# Addressing the Burden of Home Dialysis on Patients and Care Partners

Dr. Emilie Trinh

March 7, 2021

Annual Dialysis Conference

# Disclosures

- No conflicts of interest to declare.

# Objectives

1. Sources of burden with home dialysis
   - Psychosocial issues
   - Fear of adverse events
   - Caregiver burden
2. Risks associated with therapy discontinuation
3. Strategies to help alleviate burden
4. Future research direction

# Background

- Utilization of home dialysis has grown worldwide in recent years
- Evidence of both clinical and quality of life benefits with home dialysis modalities (PD and home HD)
- With efforts to increase home dialysis uptake, it is important to recognize that “one size may not fit all”
- For some patients and/or their care partners, home dialysis may lead to burden
- This may be especially true for those who are not convinced that home dialysis the best option for them

# Psychosocial issues

- Social isolation
- Illness intrusiveness
- Anxiety and/or fatigue leading to burnout
- Interaction with daily activities
- Sleep disturbances
- Body image issues with access (vascular access or PD catheter) and/or weight gain associated with therapy
- Direct financial stress associated with performing dialysis at home

# Fear of adverse events

- Complexity of home dialysis therapies → uncertainty as to the ability to adequately perform dialysis at home
- Constant responsibility and time require for preparation and completion of therapy

- HHD:
  - Fear of machine complications
  - Difficulties with vascular access cannulation
  - Self-adjustment of ultrafiltration

- PD:
  - PD catheter dysfunction
  - Cycler alarms or malfunction
  - Fear of infectious complications

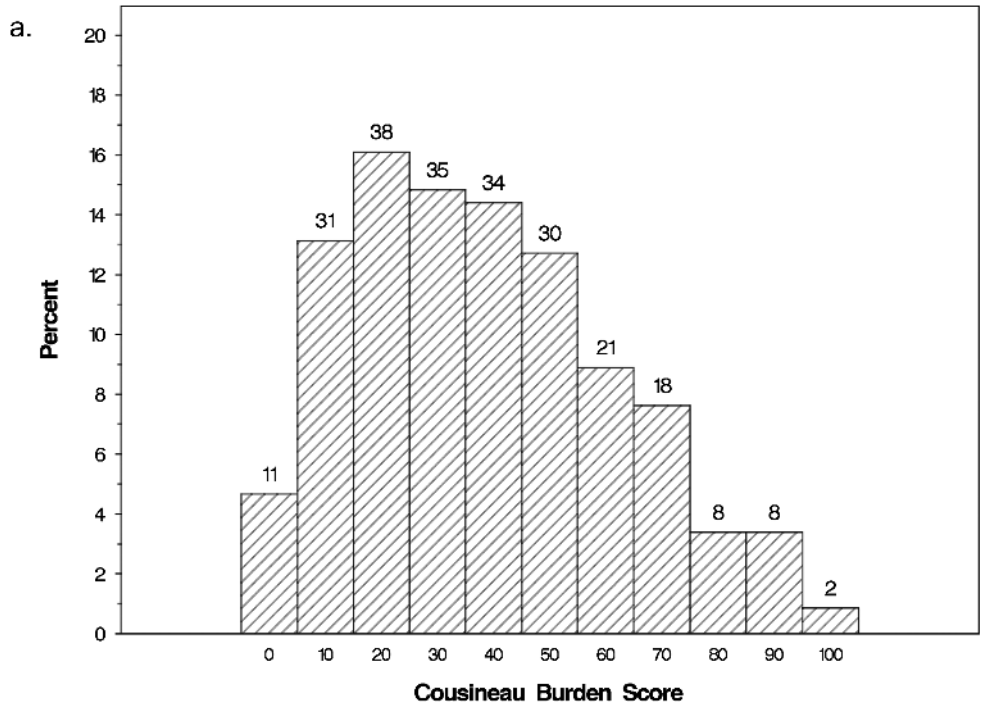
# Caregiver Burden

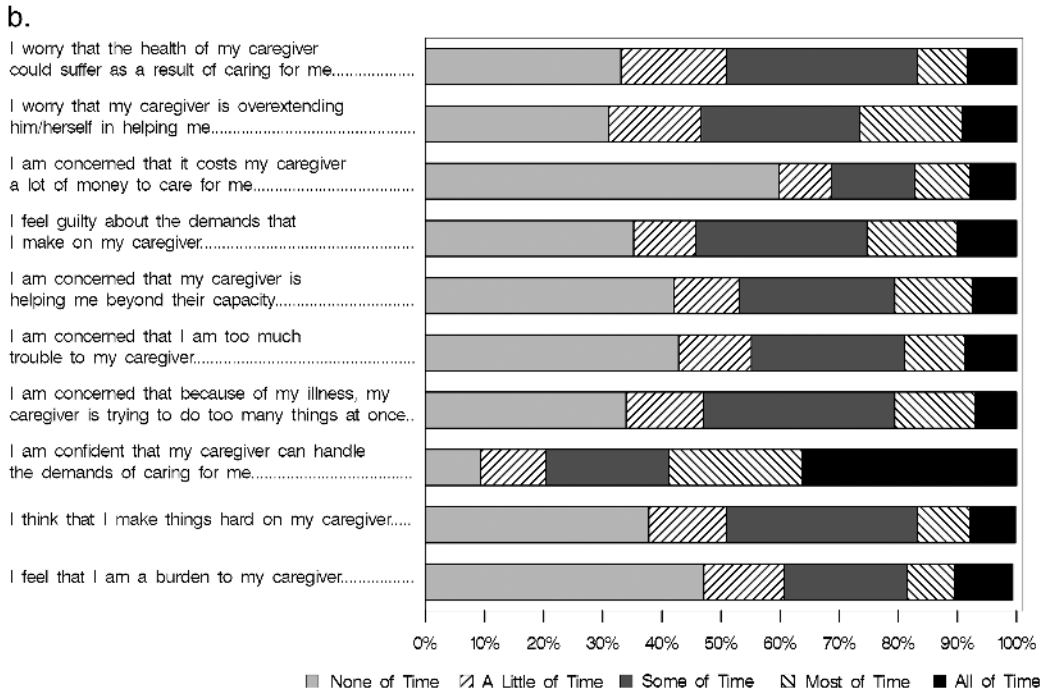
- Depending on a caregiver to help perform dialysis at home may lead patients to feel like a source of burden
- Worry about creating a stressful environment at home for their close ones
- Demands associated with being a caregiver may lead to psychosocial issues in the caregiver themselves

# Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials

Rita S. Suri[1], Brett Larive[2], Amit X. Garg[1], Yoshio N. Hall[3], Andreas Pierratos[4], Glenn M. Chertow[5], Irina Gorodetskeya[6], and Alan S. Kliger[7] for the FHN Study Group

Perceived caregiver burden in the FHN trials




*Higher perceived burden associated with lower SF-36 PHC scores, lower SF-36 MHC scores and higher BDI scores*

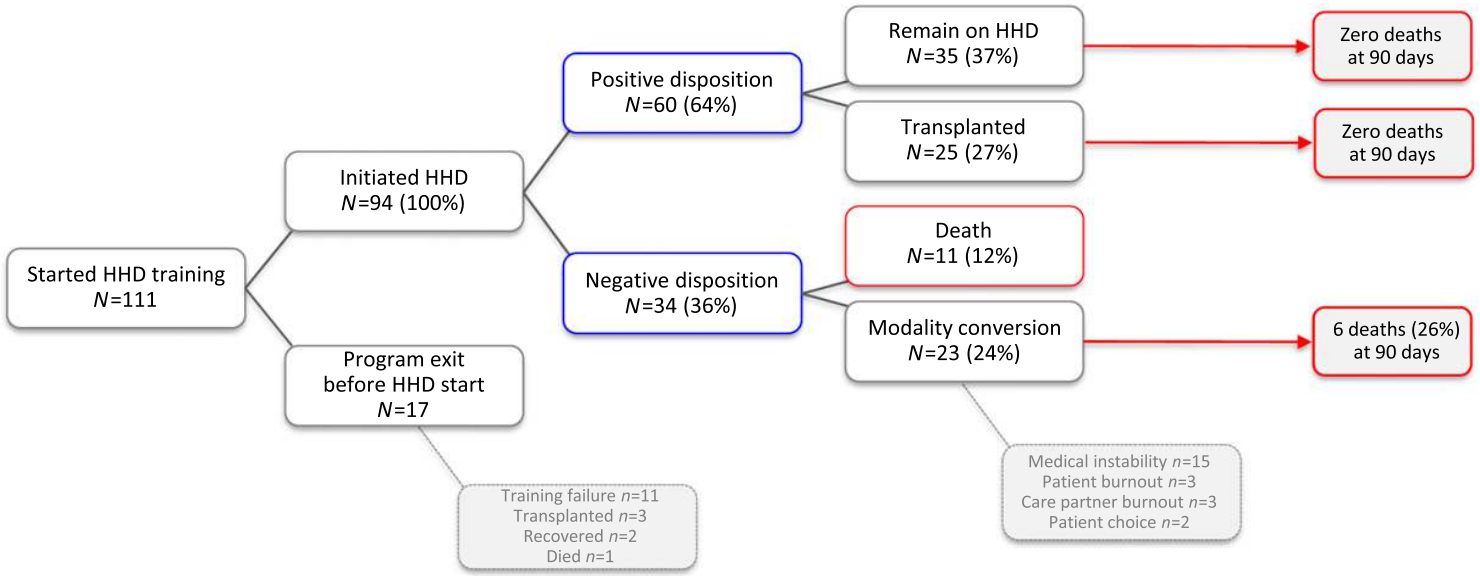
Suri et al. Nephrol Dial Transplant 2011; 26(7): 2316-2322.

# Risks associated with therapy discontinuation

- Ongoing sources of burden may lead to burnout and consequently therapy discontinuation → unplanned transition to in-center HD
- Transition period to in-center HD is a vulnerable time for patients and is associated with higher mortality and morbidity
- Therefore, it is crucial to choose the right patients for home dialysis

# Quality Assurance Audit of Technique Failure and 90-Day Mortality after Program Discharge in a Canadian Home Hemodialysis Program

*Nikhil Shah,* Frances Reintjes,† Mark Courtney,*† Scott W. Klarenbach,*† Feng Ye,*‡ Kara Schick-Makaroff,§ Kailash Jindal,*† and Robert P. Pauly*†*




Shah et al. *Clin J Am Soc Nephrol.* 2017; 12: 1259-1264

# Strategies to Alleviate Potential Burden

- Early comprehensive education of risks and benefits with home dialysis
- Early identification of concerns and fears
- Early identification of support structure
- Multidisciplinary team is crucial
- Involving a family member and/or close ones in modality education and discussion

# Strategies to Alleviate Potential Burden

- Meeting with other home dialysis patients
- Extra training time if deemed necessary
- Possibility of remote monitoring

# Strategies to Alleviate Potential Burden

- Flexibility with the treatment prescription itself
- Consideration of incremental PD/home HD may help certain patients
- Use of assisted therapy (particular PD)
- Option of a paid helper can be considered
- Short-term respite dialysis care

# Future Direction

- Future studies should place more emphasis on patient-centered care by helping identify higher risk patients and strategies to improve patient-reported outcomes
- By elucidating what is important for patients, this will allow us to optimize how we deliver care
- Research on strategies to deal with psychosocial issues and how to alleviate burden needed

# Questions?

# Understanding the Views of Patients & Care Partners

Melissa Bensouda, solo HHD patient
Michael Howington, HHD care partner
Connie Stoner, PD care partner
Beth Witten, MSW, ACSW, LSCSW, Facilitator

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# Disclosures

- Melissa Bensouda - National Dialysis Accreditation Commission Advisory Board
- Michael Howington - nothing to disclose
- Connie Stoner – nothing to disclose
- Beth Witten - National Dialysis Accreditation Commission's Advisory Board

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# Discussion Points

- What do patients and care partners consider when choosing a treatment?
- How reality based is education about home dialysis?
- How do patients and partners negotiate tasks?
- How can clinics encourage/support home dialysis?

# How did you or the person you care for choose home dialysis?

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# How is being a care partner or doing solo dialysis different from what you imagined?

# How comfortable do you feel asking for help from the patient, dialysis clinic, or others?

# What kinds of help have you needed and asked for from the dialysis clinic?

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# What could dialysis clinics do to make it easier to be a care partner or do solo dialysis?

# What advice would you give to someone who is considering solo dialysis or being a care partner?

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