

# NARRATIVE MEDICINE AND CAREGIVING FOR MEMORY-RELATED CONDITIONS

Hailey Haffey, Ph.D.



# WHAT IS NARRATIVE MEDICINE?

“I use the term Narrative Medicine to mean medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness.”

—Rita Charon, *Honoring the Stories of Illness*.

Narrative Medicine sees stories as the foundation to the body’s condition.

Providers of all medical disciplines study Narrative Medicine and its methods to learn to read their patients and their patients’ lives closely, so as to best understand the signification or meaning of their words to the stories of their bodies.

# WHAT IS NARRATIVE MEDICINE?

Possibly the best and most succinct definition:

“Narrative Medicine is clinical practice fortified by knowledge of what to do with stories.”

–Rita Charon, Ted Talk, *Honoring the Stories of Illness*

# WHAT IS NARRATIVE MEDICINE

“I came to understand that what my patients paid me to do was to listen expertly and attentively to extraordinarily complicated narratives—told in **words, gestures, silences, tracings, images, laboratory test results, and changes in the body—and to cohere all these stories into something that made provisional sense, enough sense, that is, on which to act.**”

—Rita Charon, *Honoring The Stories of Illness*



# WHAT IS NARRATIVE MEDICINE?

## **Key Method: Close Reading**

Close Reading is derived from formal literary theory.

In literature, we can ask: What is the text bringing to you?

In medicine, we can ask: What is the patient bringing to you?

We can ask ourselves:

How do we interrupt our own reading and listening thinking we already know the answer?



# WHAT IS NARRATIVE MEDICINE?

Things to consider in a close reading include attention to how the patient or caregiver uses the following **literary devices**:

**Time**

**Voice**

**Setting**

**Space**

**Mood**

**Perspective**

# HOW IS NARRATIVE MEDICINE PRACTICED?

Using literary devices for strategic reading builds  
**Narrative Competence.**

**Narrative Competence** can be defined as

“the fundamental human skill of recognizing, absorbing,  
interpreting, and being moved to action by the stories of others.”

(Charon)



# HOW IS NARRATIVE MEDICINE PRACTICED?

According to Charon, Narrative Competencies are “compassion’s prerequisites.”

Building Narrative Competence is also an excellent way to help uncover our own biases and to learn to ask better questions.

More, for a provider have compassion is to develop that key quality of what Sayantani DasGupta calls “**narrative humility**,” which in turn allows the provider to learn from the patient.

# TRANSLATING NARRATIVE MEDICINE FOR CAREGIVER INTERVIEWS

Using Principles of Narrative Medicine to Help Nurses in  
Training Learn About Narrative Competence

and

Strategies of Using Patient and Caregiver Stories as  
Foundations to Clinical Care



# OUR METHODS

The narrative situation of patients with a memory-related condition is often mediated by caregivers.

Our model features caregiver narratives in order to

- 1) Show how caregiver and patient stories are interwoven, and
- 2) Show how better care can be provided through close reading these shared stories.

Our model prioritized CHW-mediated access to caregivers in diverse communities to honor diverse stories and wisdom as these concepts relate to patient/caregiver dyads or systems.

# OUR METHODS

**Goal:** Use Narrative Medicine to Help Train Nurses Caring for Those With Memory-Related Conditions

Thanks to two key groups who provided contacts:

## **Collaborative Multi-Condition Caregiving Initiative**

-Provided contacts for caregivers who had expressed interest in further engagement.

## **Utah AHEC**

-Provided contacts for Community Health Workers (CHWs) who, in turn, connected us with members of the communities they cared for who wanted to share stories.



# OUR METHODS

8 individual caregivers interviewed

1 provider interviewed

4 caregivers from Collaborative Multi-Condition Caregiving Initiative

4 caregivers from contacts with CHWs

These 4 CHWs and their contacts represented the following communities:

African American

Spanish Speaking/Latinx

Pacific Islander

African Immigrant/Refugee



## OUR METHODS

### Guiding Question:

**What would you like healthcare providers in training to know about your situation as a caregiver to help provide you and the person you care for with better care?**

# TILE



Lessons from Tile:

Transformation through care and positivity

Learning to ask the right questions



# RON AND GAIL



Lessons from Ron and Gail:

The value of looking for signs of stories that the patient can't tell

Transformations through kindness

# JACQUELINE



Lessons from Jacqueline:

The ways caregivers close read the patient's situations

The ways that caregivers close read the care the patient receives

# LESSONS FROM OUR COLLABORATION

## **Wishlist of Caregivers for Providers:**

Slow down.

Convey positive energy.

Act with kindness and gentleness

Be sensitive to the fact that patients feel deep shame for not remembering things.

Expand geriatric-specific training.

Engage in memory-care training.

Offer additional resources to caregivers.

Pay sincere attention to cultural context.

Pay interested attention to the details of a story.

Caregivers need to feel as if the person they care for is being treated with dignity.

# THANK YOU!

## Works Cited:

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## For more information contact:

[hailey.haffey@nurs.utah.edu](mailto:hailey.haffey@nurs.utah.edu)

