

Wandering in the Patient Narrative: Opportunities to Fully Engage

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Working Fully in the Patient Narrative

Encompasses:

- Exploration of the entire patient experience
- Expression of both health and illness
- Assuring goals of care align with patient goals/values
- Directed and intentional facilitation for clarification of unique holistic needs/values

Complexity of Engagement

- Stand steady with conflict
- Allow for expression of grief, loss, anger, and frustration
- Be fully present
- Maintain neutrality
- Actively listening



Ethical Underpinnings

- Goals of care must include collaboration with patient and the entire narrative (Denny & Guido, 2012)
- The narrative of the “other” contains the essence of how to care (Paulsen, 2010)
- The story of the patient’s past and sense of “what is” shapes the interaction and allows for openings to redefine what he/she needs and develop answers (Nelson, 2012)

Clinician Barriers



- Lack confidence
- Do not recognize opportunities
- Unable to keep own values and opinions separated from engagement with patient
- Little or no formal training or self-perceived lack of education
- Constraints on time
- Personal discomfort with expressions of suffering
- Lack of understanding of meaning/purpose of suffering

Patient/Family Barriers

- Discomfort with expressing or interpreting experiences which reveal “authentic self”
(Murphy & Aquino-Russel, 2008)
- Lack communication skills
- Social taboo to discuss own dying
- Used to communication with clinicians as adversarial/disjointed (Kaufman, 2005)
- No frame of reference for exploration of feelings/values
- Cultural use of euphemisms, symbols, or experiences which seem unrelated to topic
- Current crisis may not fit with past coping mechanisms and lack skill to fit this story into new reality



Moving Past the Pain

- Patients move past the pain into self-awareness which offers meaning (Yang, Staps, & Hijmans, 2010)
- Clinicians learn to identify opportunities to “wade in the water” with patients



Don't just dangle your toes in the water, but wade in!

Narrative Chaos

- Wander in and get your feet wet
- Sort through the story
 - Acknowledge many stories are part of one
- Spend more time listening than talking
- Use empathetic statements and body language to demonstrate engagement with the stories
- Provide explicit support



Conversation

- Derived from Latin “*conversari*”
 - To turn about within
 - “*vertere*”
 - To turn
 - “*con*”
 - Together among



Shipley, J *Dictionary of word origins* (New York, Philosophical Library 1945: 95)

Key Communication Techniques

- Coaching
- Reflection
- Use of symbols and metaphors
- Showing empathy
- Intentional silence/active listening
- Tailored scripts, mnemonics, and cue cards

Framework for Caring

- “Catching up” with parts of lived narrative, what has changed and what is unrealistic promotes:
 - Change
 - Continuity
 - Allows patient to challenge notion of authentic self-expression and reframe hopes and healing
 - Shared decision-making
 - Validates caring

Shifting Focus:

- Revise Goals & Values
 - “What do you really enjoy doing now?”
 - “What is most important to you now?”
 - “If cure or control is not possible, what’s the next best thing?”
 - “If you were to hope for the best but prepare for the worst, what would that look like?”
- Create an environment of cultural humility
- Allow both conflict and consensus

Recognition of Existential Suffering

- A crisis that impacts the essence of one's being
 - Realization of the finiteness of a life-limiting illness
(Yang, et al., 2010)
- Recognition can strengthen advocacy
 - Facilitate identification of interventions and outcomes based on patient—defined goals
 - Both can discover a deep new level of meaning
 - Richer of spirit
 - Defined as more than he/she was before
 - Create a climate for self-reflection
 - Helps patient to reframe answers in a way that is understood
 - Ability to reflect on tasks undone, priorities, and growth/transformation

Case Study Examples

- Elderly man, in hospital for over 1 month
 - Widespread metastasis and multisystem involvement from cancer
 - Prognosis of 2 weeks by physician
 - Sent to evaluate understanding as patient acting “too happy” and to make sure he “got it” so that they could move forward with discharge

- 88 year old man declining rapidly since admission to hospital for a fall
 - Had been living independently
 - Now needing full assist for all care needs
 - Close to death several times due to complications from chronic illnesses
 - Getting more frustrated and prone to angry outbursts
 - Discharge planning compounded by family insistence he not be told how sick he really was and refuse hospice referral

New Opportunities



“Wading in the water, standing and letting the waters of the narrative wash over oneself by actively listening to the narrative of another demonstrates caring. In this caring model the clinician holds steady in the suffering of another, shows a willingness to understand, and helps the patient to express different possible futures for living authentically. Small steps become a leap into caring at a new level of being together in the narrative”.





"I have stuff to do, I have to go home now"

AI, 2010

Be Advised...



Be Willing to Get Your Feet Wet!

References

All references for this presentation are listed in published literature review:

Tadel, P. (2014). Wading in the water: A case study approach to engaging more fully in the patient narrative. *Illness, Crisis & Loss*. 22(1) 11-27.