Being Known: Mitigating Existential and Spiritual Distress in the Care of the Person

Presentation for Graduate Nurses

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BEING KNOWN

We are conceived within a relationship, born into a community of relationships and develop as a person through relationships. When our life becomes fractured, our relationships, with ourselves and others, are disrupted. Experiencing limitations due to health concerns, or concerns that have affected our health may bring on existential/spiritual distress.

Mitigating existential and spiritual distress in the care of a person, who has become a patient, is to help support the re-establishment, or create new avenues, of relationships. There are various tools to assess where one has landed in this new landscape with its fractures. Such assessment may give rise to a care plan with interventions* to help mitigate distress.

Any intervention must be nested within the foundation principle of gift: for one offering a gift of presence that honors and makes way for the beauty within and of the person to emerge and for the person to experience the felt feeling of being seen and known as gift.

TO BE KNOWN, IS GIFT

PALLIATIVE CARE FRAMEWORK

The focus of palliative care is to provide specialized care for people living with a serious, complex, or terminal illness. The goal of Palliative Care is to mitigate suffering. It aims to increase the patient's quality of life as the condition progresses, rather than only treat the disease or its symptoms. Palliative care can occur at any stage of illness, and it can be provided alongside curative treatments.

THE HUMAN PERSON

The model of the human person in health care today regarding assessment and treatment within the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) has been expanded with an:

anthropology of human person as a psychophysical, sociocultural situated, spiritual being

And with this view of the person, based upon acceptable research, spirituality and religion can play a role in supporting and enhancing the physical and mental health of patients. Therefore, it should be part of the assessment and care of the person as patient.

HEALTH, DISEASE, ILLNESS

"DISEASE, THEN, IS SOMETHING AN ORGAN HAS; ILLNESS IS SOMETHING A MAN HAS."

– Eric J. Cassell, 1978

We have no biomarkers for the illness (KS)

Disease is the pathophysiology, while illness is the experience of living through the disease. We can measure biomarkers of the disease framework yet within the ''illness", cannot measure feelings and frustrations. For chronic illness or even severe acute states the effects of the experience of the illness lingers for longer after the 'recovery'.

HEALTH

"Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". WHO

Note: I have not yet met a person who is in a state of complete state according to this definition.

"Health is the dynamic tension. Towards physical mental, social and spiritual harmony not only the absence of illness, which gives him the ability to fulfill the missions that has been entrusted to him, according to the state of life in which he finds himself." St. Pope John Paul II

Note: Someone can be emotionally or spiritually 'healthy – in harmony' in the midst of a physical disease.

DISEASE

"Disease – best refers to an abnormal condition affecting an organism. This abnormal condition could be due to infection, degeneration of tissue, injury/trauma, toxic exposure, development of cancer, etc."

"https://docente.unife.it/judithteresa.balari/extra-material/articles/disease-vs-illness.pdf

ILLNESS

“Illness – best refers to the feelings that might come with having a disease. Sensations or feelings like pain, fatigue, weakness, discomfort, distress, confusion, dysfunction, etc. – are the reasons people seek healthcare –and usually, the way people measure their success with treatment.

It’s very important to understand that feelings of illness can be vastly affected by many non-disease factors, such as expectations, beliefs, fears, feelings/moods, and culture. Being ill is a very personal experience, and can vary tremendously and be affected by very different things between people with the same ‘disease’."

"https://docente.unife.it/judithteresa.balari/extra-material/articles/disease-vs-illness.pdf

REACTIONS

One’s initial reaction to being diagnosed as an experience of desolation – distress where one can become angry, withdrawn, hostile or aggressive with anxiety and depression. Once one accepts their disease/injury and are able to face the reality with a sense of humble acceptance, they may experience a sense of consolation – peace.

NEEDS, DESIRES, LOSS, COPING

7 Universal Innate Desires

Our lives are shaped by the things we desire. Thomas Merton

1. To be seen
2. To be heard and understood
3. To be affirmed
4. To be held
5. To be chosen
6. To be blessed
7. To be safe

Note: Listening within the Fragmented Narratives for fulfilled or unfulfilled desires.

3 Basic Needs for Well Being

- Autonomy
- Competency
- Relatedness

Loss

When a person becomes a patient, they enter into a new and very different world. Examples of objective and subjective losses when one experiences an illness:

- Loss of Self Identity
- Loss of Independence & Autonomy
- Loss of Certainty & Control

Coping

Coping is strategy way to reduce our internal negative emotions/feelings as we try to address a stressor challenge, either proactively or reactively (overlapping with our built in defense mechanism), such as when our deepest desires, basic needs, or perceived wants are not met. The strategies can be healthy or unhealthy (maladaptive).

Four areas in coping strategies: problem-focused, emotional-focuses, support seeking, and meaning-making coping.

1. Problem-focused strategies – taking control, informal seeking and evaluating pros and cons.
2. Emotional-focused coping strategies – managing emotions via releasing pent-up one, distracting or distancing, relaxation practices such as meditating, seeking social support, reappraising, accepting.
3. Support Seeking – Reestablishing and creating new relationships to self and others.
4. Meaning- Making: reformulating former activities that were meaningful or finding new avenues that are meaningful.

Maladaptive coping examples: avoidance, disengagement, self-blame or dissociation, self-medication.

DISTRESS, PAIN, SUFFERING

DISTRESS

One experiences distress when one feels unable to cope or out of their depth, stress that negatively affects one's ability to function optimally. Overwhelmed to point of panic, and or overcome by a sense of dread. An experience of disquietude, heartache, and or malaise.

PAIN

The pain is usually described in neurological terms as a somatosensory perception that signals the individual that tissue damage has or is occurring, thus forming a mental image in the brain followed by an unpleasant emotion as well as changes in the body that tissue damage has occurred (called nociception).

Yet the experience of pain, pain tolerance or one's pain threshold is based upon one's perception of pain that is influenced by one's cognitive awareness, interpretation, behavioral disposition , and one's educational and cultural factors.

Today we look to the understanding of the human person as a **psychophysical, sociocultural situated, spiritual being** and their experiences to relieve pain and suffering. Pain and suffering are experiences which affect the whole person. Both have bodily, psychological, and social cultural, and existential or spiritual dimensions.

Mental and spiritual pain will drive one toward the inside of oneself.

SUFFERING

Suffering is an all-encompassing state within the human person – it's **an embodied experience.**

Suffering is an anguishing experience beyond pain, it involves the whole person - one's physicality, their mental and emotional state, beliefs, expectations as well as their spiritual orientation. Its source may not originate from an illness or physical pain, though it can cause one to develop dis-ease then disease. Sources of suffering can also be social problems such as poverty, relationship concerns, grief.

On the existential dimension there are two universal characteristics experiencing of suffering:

1) 'as an alienation of the self 'or
2) as an 'unhomelike being in the world'

Suffering may be so extreme that someone may not know why, or they may be unaware of their own suffering. Such sufferings can be gleamed from stories that we tell ourselves that are partial and fragmented.

Note: The importance of the Narrative – listening for and catching the fragments

EXISTENTIAL & SPIRITUAL

EXISTENTIAL & SPIRITUAL CONCERNS (KS)

- Identity - unclear sense of who I am and how one fits into the world, conflicts between the self and different aspects of oneself as it relates to others (Relatedness).
- Freedom - Blurred or confusing boundary between the experience of free will and the external forces and the complex array of alternatives (Autonomy).
- Isolation -a longing need to feel and be connected, versus the experience of not being seen or known (Desires).
- Meaning - the desire to believe in a life that is meaningful versus the events and experiences that appear to be random and inconsistent with one's belief.
- Death - awareness of its inevitability, and desire for continued existence.

EXISTENTIALISM

"A physiological inquiry that explores the problem of human existence and centers on the subjective experience of the person's thinking, feeling, and acting. It explores the meaning, purpose, and value of human existence where the human person is compelled to find or create their own sense of meaning and purpose in a meaningless world to achieve selfhood. " Wikipedia

EXISTENTIAL CONTEXT (KS)

Is one's search for meaning to make sense of one's life events, relationships, and oneself within one's subjective experience, perceptual outlook, comprehension, and interpretation of their world.

Implicit in the question(s) is what it is to be human?

1. Who am I? (now, then, future)
2. What is my purpose?
3. Where am I going?

- What is the meaning of life?
- Making sense of it all. What?
- When not making sense of it all
    - Angst , Suffering

SPIRITUALITY

SPIRITUALITY DEFINED (KS)

Spirituality is defined as one expression of one's beliefs and values in which they find meaning and purpose (KS).

It is most often associated with having a sense of connection to something larger than oneself such as a family, community, nature, or a transcendent being*.

The expression and meaning may be found in a community in the form of organized religion with its set of beliefs, and expectations in behaviors, rites, and rituals. For examples: a personal relationship with a transcendent divine being in the Abrahamic monotheistic traditions: YHWH(G_d), Triune God (Abba, Jesus, Spirit) or Allah; or in a philosophical tradition nontheistic such as Buddhism or multi theistic such as Hinduism.

Meaning may be found in an individual expression through what one loves such as art or music or one's vocational mission, or one's own experience of something transcendent that can include a desire for an attachment to a transcendent energy (the Universe, Other, Higher Power), or not (no transcendent 'entity' exists).

Overall is it now considered what are the connections that are expressed which provide a sense of comfort, peace, guidance, and a source of strength – way of being in the world, a way of proceeding in the world.

CAUSES, SYMPTOMS, AND SIGNS OF EXISTENTIAL DISTRESS

WHAT IS EXISTENTIAL DISTRESS?

Is when one is unable to find answers to their questions on the meaning and purpose of their life. It can range from areas such as uncertainty about their life goals, their identity, or more seriously the meaning of their existence in viewing it as in a meaningless world.

The essential question surrounding existential crisis is whether or not there is any pre-existing meaning to a person's life or life itself.

WHY IS IT TRIGGERED OR WHEN CAN IT OCCUR?

An event that changed one's life such as coming to terms with what's mortality or confronting a life-threatening illness.

SYMPTOMS

- Emotional Symptoms: Feeling of helplessness, or despair, vulnerability, fear, loneliness, anxiety, not feeling true to oneself. Feeling disconnected from oneself and others in the world.
- Cognitive symptoms: Thinking that life has lost its purpose, thinking that one has lost their values, or ideas about oneself, negative thoughts, regret, disappointment
- Longing for a ground in a world that seems groundless (seeking stability – signs).

SIGNS

- Breaking off relationships, substance-abuse, antisocial behavior
- Blocking off emotions or feelings that they struggle with
- Difficulty in making decisions
- Anxiety, Sleep Disturbance
- Loss of interest in daily activities

OVERCOMING AN EXISTENTIAL CRISIS

- Breaking down the larger questions into smaller chunks
- Keeping a gratitude journal, reflecting on the daily interactions of positive experiences
- Become aware of negative thought patterns seeking help to reduce the negative self-talk
- Reconnected or reconnecting with loved ones
- Redirecting energy to other activities

CAUSES, SYMPTOMS, AND SIGNS OF SPIRITUAL DISTRESS

WHAT IS SPIRITUAL DISTRESS

Spiritual distress, as in Existential distress, occurs when a person is no longer able to find meaning, peace, comfort, strength, and or connections in their life.

Spiritual distress can be characterized by an expression of a deficit of meaning, purpose, hope, forgiveness, and or intimacy with the divine; and or anger or lack of interest in previously spiritually or religiously nourishing activities.

SPIRITUAL DISTRESS A DEFINITION

"Spiritual distress has a nursing diagnosis (NANDA International) of impaired ability to experience and integrate meaning and purpose in life through the individual's connectedness with self, others, art, music, literature, nature, or a power greater than oneself. This definition corresponds well with the consensus definition of spirituality: spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices." https://www.jpsmjournal.com/article/s0885-3924(17)30187-2/fulltext

CAUSES OF SPIRITUAL DISTRESS

- Broken relationships - with family, community, or the Transcendent (Other) as they understand and believe
- Loss of Meaning/Purpose - with one's health, work
- Shame/Guilt/ Forgiveness - from others upon them; from themselves upon themselves, or on others, or the Other; restoration
- Hopelessness - due to helplessness

SYMPTOMS (KS)

- Feeling a loss of hope, empty, directionless
- Sense of failure to live within one's beliefs or the precepts of one's faith
- Feelings of abandonment (by their High Power)
- Fear related to apprehension about the soul's future after death
- Anxiety from feeling they are not sufficiently prepared for death

SIGNS (KS)

- Sleep Disturbance
- Anxiety/Depression
- Changes in religious or spiritual practices
- Expressing disappointment in one's current belief system
- Questioning the credibility of their belief system
- Demonstrating discouragement or despair
- Inability to practice through usual religious rituals
- Decisional conflict - between the treatment plan and current versus past beliefs
- Expressing concern, anger, resentment, fear, over the meaning of life suffering and death
- Lethargy or lack of interest
- Outbursts

STATEMENTS

Spiritual Pain of Relatedness - *My family has forgotten me*

Spiritual Pain of Meaning - *My life has no purpose*

Spiritual Pain of Forgiveness - *My life is full of shame and guilt*

Spiritual Pain of Forgiveness Hopelessness - *I just want to die here*

Asking questions about pain and suffering - *Why is God doing this to me?" "Why is God allowing me to suffer?" "Where is God?"*

ASSESSMENT TOOLS

GOAL FOR HEALING(KS)

Reconnecting, Reassessing, Renewing, Regenerating

Assessment tools are designed to elicit what are beliefs, values, practices that are supportive to the patient that have been and or are meaningful.

- Spiritual screening – *Do you want to see Chaplain*?
- Spiritual history - the process of interviewing the patients to have a better understanding of their needs and resources (FICA, HOPE)
- Spiritual assessment –is defined as the ongoing process of active listening to the patient's story as it unfolds in the relationship and summarizing the needs and resources that emerge in the process, and summarizing a care plan with expected outcomes to address spiritual distress to support well-being

INFORMAL SPIRITUAL ASSESSMENT

Informal spiritual assessment can occur at any time during an encounter with a patient.

The Narrative

Patients use symbolic and metaphorical language when expressing their spiritual thoughts. The spiritual assessment often involves listening carefully to the stories of patients regarding their lives and illness. The themes that emerge are the search for meaning, feelings of connection versus isolation, hope versus hopelessness, and fear of the unknown, which are clues that they may be struggling with spiritual issues.

FORMAL SPIRITUAL ASSESSMENTS

INITIAL HOPE ASSESSMENT

Categories and Suggested Questions:

H – sources of hope – meaning, comfort, strength, peace, and connection
O – organized religion
P – personal spirituality and practices
E – effects on medical care and end of life issues

H: Sources of hope, meaning, comfort, strength, peace, love and connection

- We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support?
- What are your sources of hope, strength, comfort and peace?
- What do you hold on to during difficult times?
- What sustains you and keeps you going?
- For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you?
- If the answer is "Yes," go on to O and P questions.
- If the answer is "No," consider asking: Was it ever? If the answer is "Yes," ask: What changed?

O: Organized religion

- Do you consider yourself part of an organized religion?
- How important is this to you?
- What aspects of your religion are helpful and not so helpful to you?
- Are you part of a religious or spiritual community? Does it help you? How?

P: Personal spirituality/ practices

- Do you have personal spiritual beliefs that are independent of organized religion? What are they?
- Do you believe in God? What kind of relationship do you have with God?
- What aspects of your spirituality or spiritual practices do you find most helpful to you personally?
    - (e.g., prayer, meditation, reading scripture, attending religious services, listening to music, hiking, communing with nature)

E: Effects on medical care and end-of-life issues

- Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?)
- Is there anything that I can do to help you access the resources that usually help you?
- Are you worried about any conflicts between your beliefs and your medical situation/care/decisions?
- Would it be helpful for you to speak to a clinical chaplain/community spiritual leader?
- Are there any specific practices or restrictions I should know about in providing your medical care? (e.g., dietary restrictions, use of blood products)

HOPE ASSESSMENT MULTI- MODEL

Four areas for Assessments, Questions, Outcomes

1. Concept of the Holy
2. Self/Illness
3. Support System
4. Hope

CONCEPT OF THE HOLY

THE HOLY: Assessment

- What does patient hold sacred. Or is in awe of.
- Is there an awareness of the holy. Faith.
- Does person consider grace, blessings, and sense of the generous.
- Salvation: ability to move from darkness toward light, well-being, wholeness

THE HOLY: Questions

- *Do you have a sense of where God is in all of this?*
- *How has your relationship with God sustained you?*
- *Are there spiritual or religious practices that have been especially helpful?*

THE HOLY: Outcomes

- Repentance: ability to move from anguish/sins toward well-being and forgiveness
- Identify chaplain as a safe person who will support a relationship with the Holy
- Access relationship to God/The Holy/the higher power
- Encourage/reinforce their use of religious and spiritual practices

SELF/ILLNESS

SELF/ILLNESS: Assessment

What is their :

- Ability to trust
- Ability to mourn and re-engage
- Ability to create/make meaning
- Ability to progress through life's developmental phases
- What is the nature of patient's relationship to the crisis
    - Victim? Conqueror? Fear? Acceptance?

SELF/ ILLNESS: Questions

- *What is giving you strength to cope right now?*
- *What is the hardest thing about this time for you?*
- *How have you dealt with previous loss, disappointment, illness?*

SELF/ILLNESS: Outcomes

- Access inner resources for healing
- Access convictions and regain direction and energy for healing
- Clarify problem areas
- Identify options

SUPPORT SYSTEM

SUPPORT SYSTEM: Assessment

Significant Others

- Potential to learn about God, the Holy, through personal relationships
- Ability to explore significance of difficult relationships such as estrangement, divorce, loss

Community

- In which person finds meaning in relationship to ultimate values
- Spiritual home-place of comfort
- Accountability-place to matter in the larger world
- Significant religious/spiritual practices
- Place to be prayed for, remembered, mourned

SUPPORT SYSTEM: Questions

- *Who is there for you in this time?*
- *Who do you most miss?*
- *Where do you feel you most belong?*

SUPPORT SYSTEM: Outcomes

- Person accesses the meaningfulness of their community during this crisis
- Person pinpoints losses in relation to community, moves from grief to love
- Experiences support and guidance in summoning resources of community

HOPE

HOPE: Assessment

- Is there a future?
- What does it hold for person?

HOPE: Questions

- *What are you most looking forward to?*
- *What helps you when you are feeling blue?*
- *How do you comfort yourself?*
- *If the patient speaks of fear of dying…What specifically are you afraid of?*

HOPE: Outcomes

- Gains perspective on current situation
- Achieves clarity about problem areas
- Reaches general sense of well-being

FICA MODEL

F- Faith and Belief:

- *Do you consider yourself spiritual or religious?*
- *Do you have spiritual beliefs or practices that help you cope with stress?*
- *If no – What in your life gives you meaning or strength*?

I – Importance:

- *What importance does your faith or belief have in your life?*
- *Have your beliefs influenced how you take care of yourself in this illness?*
- *What role do your beliefs play in regaining your health?*

C – Community:

- *Do you have a community where you feel you belong and are cared for?*
- *Are you part of a religious or spiritual community?*

A – Address

- *How, if at all, would you like me to address these issues in your healthcare?*

OTHER ASSESSMENTS

1. FACIT-Sp-12
2. Spiritual Injury Scale (SIS)
3. SPIRIT
4. FAITH
5. FACT

SPIRITUAL SUFFERING LEVELS

0. No end-of-life issues causing spiritual distress. This is for patient who has no life regrets and no family issues and is ready for death.
1. Patient puts little focus on life events which are possible sources of minimal spiritual distress during end-of-life, and most focus on issues of well-being. No recent losses; no regrets.
2. Patient puts some focus on spiritual/religious issues in their lives which cause distress but does not acknowledge distress; puts focus on drawing from sources of spiritual well-being and coping.
3. Patient expresses minimal spiritual distress from life issues, but more focus on issues of well-being.
4. Moderate distress from issues noted. Patient acknowledges the distress but continues to also focus on sources of well-being.
5. Moderate distress from issues noted, with less focus on sources of well-being.
6. Moderate suffering from issues noted, dominating the patient's focus. Patient either unable to draw from sources of spiritual well-being or has not identified sources.
7. Severe suffering from issues noted. Patient still able to draw from sources of well-being.
8. Severe suffering from one or more issues noted. Patient having difficulty drawing from sources of well-being.
9. Severe suffering from one or more issues noted. Patient unable to find relief through humor or distraction, with little or no ability to draw from sources of well-being.
10. Severe, unbearable suffering from one or more issues noted. Loss of hope; utter despair.

CHARTING

Patient's decision making as related to their religion or spirituality. The patient's sense of suffering and their coping. The emerging emotions of the patient and/or the family.

PROVIDERS AS THE DOOR TO HEALING

Note: For Conversation

- Being Authentic
- Offer Presence
- Holding a safe space
- Empathetic Listening
- Asking open non-judgmental questions
- Allow the other to be other in their unfolding
- And to let ourselves be changed by the life of another

JOINED IN A JOURNEY OF ILLNESS

As Patient: Though I stand at heaven's gate, holding onto a remembrance yet feeling far from it waiting for a miracle, within the chalice of pain I encounter another as my brokenness longs in longing to be redeemed from this immanent of experience.

As Caregiver: Traveling into the inner world of unknown darkness of another, I hold onto the light of live, keeping a vigil listening for the far off rumbles and catching the echoes of their past hopes for thy joy to be resurrected again.

'NARRATIVE MEDICINE'

IMPORTANCE OF THE NARRATIVE[1]

In John J. Cicero's essay P*ositive Psychology: A New Paradigm,* he addresses the need to allow others to communicate their narrative by refraining from interrupting, or by giving advice. This is crucial in creating an environment where the sacred can become palpable.

In looking at the theology of illness and our faith experience it has an implicit and explicit relationship with our Creator.

Cicero points to the work of Irish theologian Dermont Lane's work on the meaning hope within illness: "*hope takes energy to act, hope rises from within the person but only as an encounter with the external world of human beings for the human to exist always means to coexist and that is to be always in relationships*".

It is in an illness when we are stripped down to work out becoming receptive to many moments of grace.

THE PHENOMENA OF THE META STORY

Storytelling is the unconscious talking, *they do not know what*. Let the story break into the consciousness. If low trust in the listener or the storyteller, the story is more abstract.

Listening for these types

- Data Back Then Story
  - What I was a kid, I _____. I remember long ago _____.
  - Response: *What were the feelings back then, feelings now*, offer some self disclosure.
- Reinvestment or Rehearsal Story
  - Goes back into the past to rehearse because it has the same thematic words
  - Response: look for keywords
- I know Someone Story
  - Tells you a story about themselves as someone else
- Anniversary Story
  - A rehearsal story told at a given time of the year
- Counter Story
  - Saying the opposite.

[1] pgs. 3-19 Spiritual and Psychological Aspects of illness: Dealing with Sickness, Loss, Dying and Death Edited by Musgrave and McGettigan

Metaphor – a things, place, object, person, represents deep into the mind a symbolic form – the way the unconscious creates the metaphor… "Tree rattling inside"

Do a story check…*I was wonderful if* _____

YOU CAN NOT 'NOT' TELL OUR STORY

TYPES OF ILLNESS NARRATIVES

"Illness stories are therapeutic for *tellers* who have a real opportunity to be heard and to hear themselves. As they tell and retell their story they can unravel the truth of their own experience of illness and begin to adjust to the person they have become. From this position they can begin to uncover the person they could become. Telling their story has given them the opportunity to step outside of themselves and witness who they are. This dis-identification allows new possibilities to emerge" (Sharon Kitly).

The Restitution Story

This is a story in the medical community expects this is not the story of someone with a chronic permanent illness. The person will feel isolation and may have an increase in their suffering if they are expected to give such a narrative.

The caretaker needs to be there for them.

The Chaos Story

Paraphrased: When someone lives with unrelenting pain suffering from a chronic permanent disability or life limiting disease they may face multiple problems related to work, family, social, financial or where there is a little solution to be found.

The caretaker needs to honor the person suffering.

When they are overwhelmed by the intensity of their illness they are unable to speak coherently, for a lived chaos cannot be told. Only when they're able to stand outside the chaos killer story begin to emerge. The challenge of listening is to refrain from staring the teller away from the difficulty of telling. The listener is to hear. The narrative is often disjointed and without sequence. This particular story it's difficult to listen to by family or friends because they hope

things to return to normal and they tell her to return to their formal self. Usually platitudes or silences tend to follow (Sharon Kitly)."

When they cannot share their true story there's an increase of fear. And further upset

The Quest Story

Shea: This is when the person understands this as a learning journey where the individual believes their illness had led them to new insights and transformation. There is a sense of giving up the old, a renewal of finding, a new gratefulness to the condition. Accepting life "unconditionally" finding a new fuller sense of self, what can be reclaimed… finding a grateful life in conditions that the previously self would consider unacceptable.

There's an acceptance and a deeper meaning within the narrative for the listener to listen for.

NURTURING

For all three it is the story of the patient's journey, and it is theirs to tell.

Change can only be nurtured by the caretaker:

1. By holding the sincere belief that the story you are hearing *needs no change*
2. By helping the person '*hear exactly what story she or he is telling*
3. By helping the person know that *they are living a story that is theirs to tell*

Conversation types of Stories heard in your work

STORY LISTENING[2]

Some patients find the only way they can express their feelings is by a story. Some may have languages for their feelings, they are thinkers. We are to encourage and to respond to their stories to help them make sense of their story.

1. Help connect story to the present if they are unable
    a. statement or questions:
        - *I think I can see why you told me why you told me that story.* Or
        - *Is what happened to you then, what is happening to you now?*
    b. To gain perspective from their story– privately analyze their story
        i. what values and beliefs are revealed in the story
        ii. what life themes emerge
        iii. how does past influence the present
        iv. what unresolved conflicts are coming to the surface
        v. what might this story be as a metaphor
        vi. how does patient portray themselves?
        vii. why did they tell the story now?
2. Do a Story Check
    - Ask: *The stories you are telling me seem to have a theme about _____. Can you tell me more about them? or*
    - *I learned from your story you value _____how does that help you now?*
3. Help patients see the story in a redeeming or meaningful context
    This is your life now, how would you like your story to end
    - *What will it take you to achieve the happy ending*

[2] What do I say? Talking with Patients about Spirituality.

ERIKSON'S STAGES OF DEVELOPMENT

My personal notes and notes taken directly or paraphrased from John Shea's *Illness and the Quest for an Adult Faith*[3] . Uncovering where is the person in their development is by listening within one's narrative for key elements and what areas of 'virtues' we look to to support.

Universality of the experience of an illness
An unavoidable human condition
Illness is a developmental crisis

1. TRUST VS MISTRUST

Birth to age one
Learn from your mother, outer good becomes inner good
Okay to have bodily needs

Mistrust in Illness

- Whom can I trust?
- Can't trust my body!
- Initial loss of hope
- What people are saying to me is true?
- Can I trust God?

Support focus Trust
The Virtue of 'hope'

2. AUTONOMY VS SHAME AND DOUBT

Age 1-3
I am me, learning sense of control
Doubt comes when loss of control or shame - something wrong with who I am

Shame and Doubt in Illness

- Loss of control, too exhausted to even have will power
- Embarrassed of being taken care of, shame in the exposure and loss of control

Support focus Autonomy
Virtue is 'free will'

[3] Spiritual and Psychological Aspects of illness: Dealing with Sickness, Loss, Dying and Death Edited by Musgrave and McGettigan

3. INITIATIVE VS GUILT

Ages 3-6 Preschool
Sexuality develops
To make like, fantasy - develop to control both fantasy and action

Guilt in Illness

- *Who am I?* comes into question
- Loss of purpose in being alive
- Unable to dream of a joyful end
- Can I initiate a relationship with others, staff, God?
- Burden on the family

Support focus initiative
Virtue a 'sense of purpose'

4. INDUSTRY VS INFERIORITY

Age 6 to Puberty
Time to make things, to do a job

Inferiority in Illness

- New landscape, navigate a foreign system and language
- How to learn to be a patient
- Becoming their own advocate in a disease, patient centered or a person-centered system.

Support focus on Industry
Virtue is 'competence'

5. IDENTIFY VS IDENTITY DIFFUSION

Puberty – Adulthood
Time to be oneself, quest for identity

Identity Diffusion in Illness

- *Who am I now to myself to others? a burden? What is a sick person?*
- Loss of others - friends, uncertainly in *Who I will be?*

Focus on Identity
Virtue is 'strength to relate to others in fidelity'

6. INTIMACY VS ISOLATION

Fullness of Young Adulthood
Able to fuse your identity with someone else's without fear you are going to lose something of yourself. Danger isolation 'to be absorbed in oneself'.

Isolation in Illness

- Becoming ill isolates the self from the self and others, moving through stages from being self-absorbed to reaching out – acceptance.
- *Who will I share this most inner recess of my life?* I will locked myself.
- Fear of being not accepted, in hating God, or feeling helpless?
- Caregiver helps by - Self disclosure
- Strong attraction to staff

Focus on Intimacy
Virtue is 'love'

7. GENERATIVITY VS STAGNATION

Mature Adulthood
Time to take care of next generation.

Danger is stagnation

- *What can I do for others when I can't do for myself? What can I give myself?*
- Caregiver: Reinforce their positive decisions on living purposively whatever one can do for what time is left.

Focus on Generativity (See Dignity Therapy)
Virtue is 'care'

8. INTEGRITY VS DESPAIR

Culmination Old Age
Reconciliation or restitution, forgiveness and acceptance in choosing integrity. A time of having been, of acceptance of what was and had to be. Adjusting to the disappointments. Being happy and content.

Danger is despair, no time to start over.
Can I accept my life now as it is?
A detached concern with life itself in the face of limited time of aging or death
Accepting the ongoing chronic disease or disability

Focusing on Integrity
Virtue is 'wisdom'

4 KEY COMPONENTS TO ACHIEVE INTEGRITY OF WELL-BEING IN THE MIDST OF AN ILLNESS

- Reconciliation
- Restitution
- Forgiveness
- Acceptance

The focus is not just to be on the recovery, but the renewal.

The renewal of oneself as such is a shared process. It needs to be a dialogue in which caretaker, who in listening to the narrative of the ill person, enters into **a mutual relationship**. Both will experience a transformation in the movements through desolation and consolation in the sharing relationship.

HELPFUL QUESTIONS

IN A CRISIS- THE QUESTION

The Question: *Tell me what happened?*

Relaying the story helps break through the shock, emphasizes the reality of what has happened, reduces confusion, brings some clarity, reduces the intensity of the feelings, this conveys support and care.

A crisis is a turning point, demanding reflection and decision-making over time

- *Are you clear about what the doctor has said (is saying)?*
- *Do you have any questions you like to ask the doctors?*

DAILY VISIT QUESTIONS

- *What's going on with you today?*
- *What is your main concern now?*
- *In times like these, do you find your faith makes a difference?*
- *I've noticed that…*
- *I've heard you say…*
- *What helps you cope?*
- *I'd like to come back to something you mentioned that may be important to you…*
- *What weighs heaviest on you right now?*

THE SPIRITUAL DIRECTION QUESTION

- *What do you feel God is asking of you right now in this situation?*

PERSPECTIVE OF GOD IN FINDING MEANING IN THE SUFFERING WITHIN AN ILLNESS

Image of God needs to be renegotiated, who is God for them, how they see God being there for them in the present moment. And one needs to be willing to engage in that conversation.

Many continue to hold the image of God that one found in one's childhood.

[4]John Bickel in his essay *The Spiritual Pain of Illness*, in finding meaning in our illness or losses, he describes three different ways one can come to find meaning to these experiences:

- Punishment ("*I deserve this*")
- Mystery ("*Why is it happening to me")*
- Ultimate source of good ("*Something good can come out of this experience*")

We will hear one or more of these ways of finding meaning expressed in the person's narrative.

Depending upon where one is developmentally in their spiritual life,

God is either a *super ego God* who is a Supreme Being, the God of law, a God of dependency and control, versus the God of an adult faith who is a living God, is a *God as Thou*, it is a living God of love, and of mystery, of freedom, and of community.

Shea in his essay summarizes and restates that it is critical for a seriously ill person to be able to tell their story in order to be connected to reality in life. This is a challenge to address our image of God which we may lead us to stop believing in a super evil God, or it may leave us petitioning to God, or maybe we may begin a quest to experience the living God in relationship.

In listening to the seriously ill person, the author states that we need to be aware of what is happening developmentally to the person and that the listener honors the story by not changing it.

[4] pg. 11 Partners in Healing: Bringing Compassion to People with Illness or Loss, Paulist Press 2003

DIGNITY THERAPY[5]

All of the following has been taken from the Legacy Project under the Palliative Care Committee of the Order of Malta American Association.

This is based upon a clinical model developed by Dr. Harvey Chochinov's *Dignity Therapy* which is now used to give patients in hospices and in hospitals who are on palliative care, the opportunity to talk about their lives and preserve their history.

PRESERVING DIGNITY

"Dr. Harvey Chochinov of the Manitoba Palliative Care Research Unit in Canada, in collaboration with researchers from Australia, England, and the United States found a range of factors that either supported or undermined a person's sense of dignity. Out of the research, they developed a *Dignity in Care Model* that offers a repertoire of dignity conserving interventions as a new model for palliative care."

A DIGNITY INTERVENTION

"One of the interventions found to be most effective was a psychotherapeutic intervention that addressed generativity and legacy, one of the factors related to a person's sense of dignity. Patients were offered an opportunity to talk about their life using open-ended questions.

Different from a *Life Review* that is a historical recounting of events –this intervention supports the patient in recounting those ideas, memories, and events that are relevant and meaningful for them and what they desire to pass along to others. The term Dignity Therapy was applied to this intervention. These 30-60 minute sessions with the clinician were taped, transcribed, and edited by staff then offered to the patient to make changes before a final document is published as a legacy.

The process is initially an hour using targeted questions to stimulate memories. The sharing interview is transcribed into a draft and then a formal document. Patients have reported immense value as it provided the time and space to reflect on their lives, both the successes and challenges and to share these thoughts with those they care about. The patients receive a bound transcript of the interview to keep or give away."

[5] Taken from St. Bernadette Ministry Supporting the Dignity of Care for the Elderly, Frail, Sick, and Terminally Ill. Legacy Project for the Order of Malta American Association. Permission given. Karen Shields Wright Committee Member

ADDRESSING DIGNITY RELATED CONCERNS

More information can be found at: https://dignityincare.ca/en/faq-toolkit.html for what it means related to preserving dignity, what questions to ask, and interventions to provide to mitigate distress.

Dignity Therapy (DT) was shown to promote spiritual and psychological well-being. It helps one get in touch with what was most meaningful in their experiences and accomplishments that made them unique and valued and to do something for loved ones that will endure beyond one's own life.

Dignity Care Model

A. Illness-Related Concerns

1. Symptom distress (physical and psychological)
2. Level of Independence (cognitive acuity, functional capacity)

B. Dignity Conserving Repertoire (Psychological and Spiritual Factors: Outlook of Who NOT What)

1. Continuity of self
2. Role preservation: Survival is equal parts mental/physical fortitude & retained physical capacity
3. Maintenance of pride (positive self-regard, self-respect)
4. Hopefulness: Usually assoc. w/ "a future"; w/ meaning and purpose
5. Autonomy/Control: Loss of autonomy=loss of personhood
6. Generativity/legacy (guidance for next generation) Dignity Therapy
7. Acceptance (often easier for the elderly; comes in steps; denial provides psychological space)
8. Resilience/fighting spirit

C. Dignity Conserving Practices

1. Living in the moment
2. Maintaining normalcy
3. Seeking spiritual comfort

D. Social Dignity Inventory (Environmental/External factors)

1. Privacy boundaries
2. Social support
3. Care tenor: Mirror back to patient either "illness or personhood"; Quality NOT amount of time spent
4. Burden to Others
5. Aftermath concerns

- The Model represents current understanding of what might influence a dying patient's sense of dignity
- Dignity Model: three primary areas address: physical, existential/spiritual, and social considerations
- The text: *Dignity Therapy: Final Words for Final Days by Harvey Max Chochinov* focuses on Dignity Therapy (Generativity document) as a clinical intervention to address generativity and aftermath concerns within his Dignity Care Model.

EFFECTIVENESS OF GENERATIVITY DOCUMENT

- DT can enhance life experience for those nearing death
- DT can improve spiritual well-being, and quality of life, sense of dignity
- DT can help cope with disappointments, process the reality of leaving loved ones behind, and deal with sadness, loss, and isolation
- DT can help consider personal priorities and resolving outstanding conflicts
- DT stands on solid empirical ground; treatment is evidence based; supporting data very strong
- DT helps mitigate various kinds of stress and suffering for patients and families

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INTERVIEW QUESTIONS

1. "Tell me a little about your life history, particularly the parts that you either remember most, or think are the most important. When did you feel most alive?"
2. "Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?"
3. "What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc.)?
4. Why were they so important to you, and what do you think you accomplished in those roles?"
5. "What are your most important accomplishments, and what do you feel most proud of?"
6. "Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?"
7. "What are your hopes and dreams for your loved ones?"
8. "What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, others)?"
9. "Are there words or perhaps even instructions you would like to offer your family to help prepare them for the future?"
10. "In creating this permanent record, are there other things that you would like included?"

WHY THIS PROJECT?

Everyone has a beautiful story to tell and to share in the preciousness of passing on wisdom.

My Life Story: A Legacy Project is a way to remember and be remembered; it is one's important moments, a history as an autobiographical poem in prose in the storyteller's own words. This, as a legacy document, is for them to share with and leave for their family and friends.

Why this project? Purpose? Why is this important?

Why do we encourage a person to share their story? What benefit is there for that person?

- Their legacy to loved ones
- To be better known and understood
- As a gift of love to themselves and others, including the interviewer
- Helps in meaning making
- Helps in answering the important questions often asked as one grows closer to the end of life- Did I matter? Did my life matter? Was I loved? Did I love?

SUMMARY

Story listening is way for the listener to bring themselves to see, and the storyteller to come to be seen and known by themselves and by others. There is beauty in each of us and each has a story to share which brings more life and light into the world.

I believe we need to consider, be mindful of, what seems to me to becoming more prevalent today in the health care system (as in many business interactions) is a fragmentation in the care of a person, who has become a patient, and how that may be affecting the personhood of both provider and receiver.

Such terms as Dignity Therapy, Spiritual Therapeutics, or Narrative Medicine with their correlated 'therapeutic procedural codes ', for me begs an existential/spiritual question: Are we replacing the humanity of human relationships with a 'therapeutic relationship', where it is now, no longer a relationship, but an encounter with the 'other' that 'categorized', 'efficient' and 'transactional'?

I have found and understand the importance of creating a generativity document – a life review story - is a way for a person to share their wisdom, to share their selves with others – to be seen and known. I do not agree such should be presented or conducted within a 'procedural' code milieu. The human person is not a document.

"*In conversation you will find a new dimension of yourself. In friendship and a good conversation you will get a chance to make a clearance in order to allow the other person to emerge as who they are in their otherness, in a safe space where they will not be assaulted with either expectations or judgment. Friendship and love offer is a safe space of clearance, healing and possibilities through imagination*." John O'Donoghue