Enhancing Well-Being 2: Caring, Communicating and Decoding Distress

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Institutional Model of Care

- Reflects societal views of aging
- Values “doing” over “being”
- Sees aging as decline
- Devalues elders
- Discounts and stigmatizes people living with dementia
- Uses a “hospital” model approach to long-term care
- Provides medical and nursing care, but fails to recognize and cultivate other aspects of life
Institutional Model…

Erodes elder empowerment through:

- Personal
- Operational, and
- Physical

dimensions…
Disempowerment: Personal Dimension

Elaine Brody, MSW (1971)

- “Excess disability”—Disability that is greater than the underlying illness itself would produce
- A function of the care environment
- The good news: potentially reversible!
Tom Kitwood (1997)

- “Positioning”
- “Malignant Social Psychology”
  - Deception
  - Disempowerment
  - Infantilization
  - Intimidation
  - Labeling
  - Stigmatization
  - Outpacing
  - Invalidation
  - Banishment
  - Objectification
  - Ignoring
  - Imposition
  - Withholding
  - Accusation
  - Disruption
  - Mockery
  - Disparagement
  - Banishment
“Positive Person Work”

Recognition          Negotiation
Collaboration        Play
“Timalation”          Celebration
Relaxation           Validation
“Holding”             Facilitation
Creation              Giving
The Danger of Stigmas…

- The self-fulfilling prophecy:

  “If you expect less, that’s what you will get!”
SFP Examples

- He can’t do that because he has dementia, so we will do it for him.
- She can’t decide that, so we will decide for her.
- People with dementia cannot learn.
- People with dementia cannot grow.
- Frail elders cannot give care, only receive it.
- What examples can you think of??
Disempowerment: Operational Dimension

Often expressed through self-fulfilling prophecies

- Doing for
- Deciding for
- Excluding
- Language!
- Regimented living schedules
- Positioning and malignant social psychology
Disempowerment: Physical Dimension

- Long hallways
- Double rooms
- Nursing station
- Med carts
- Uniforms
- Beds, alarms, etc.

...cause excess disability and reinforce the “sick” role
Is “person-centered care” good enough???

- Often viewed and applied paternalistically
- Often retains many aspects of positioning, MSP and SPFs
- Organizational / departmental priorities always trump individual choice
- Positioning and SFPs are often mirrored by how management views/treats staff!!
Dr. Richard Taylor

- “My biggest challenge is to find meaning in today.”
- “I need a purposeful and purpose-filled life.”
- “I need to be enabled and re-abled.”
What We Often Hear

- “I cannot give him choices – it would be too risky.”

  OR

- “I tried to give him choices, but he didn’t seem to know what to do, so I make them instead.”

We hear this about people living with dementia.

We also hear this about employees!
Five Conditions of Empowerment

- Knowledge
- Parameters
- Training and Skills
- Resources
- Supportive Environment
How Can We Apply the Conditions of Empowerment to People Living with Cognitive Disabilities??
Levels of Empowerment

- Face-to-face communication skills
- Working at tasks
- Wording for choices
- Appreciation
Face-to-Face Approaches
At its Most Basic Level…

Good Communication Is Empowerment!!!
General Approach: Basics

- At the door → knock, identify, ask permission to enter
- Re-introduce yourself
- Sit down – face to face, eye level
- “Eye of the hurricane”
- Physical space, comfort, quiet
- Optimize hearing and vision
- Center yourself
Basics (cont.)

- Speak slowly and clearly (not loudly)
- Allow time for processing and response
- Eye contact, facial expression, non-verbal cues
- Project calm, kindness, empathy
- Appropriate touch
- Active listening (Clarify, Rephrase, Reflect, Summarize)
Other Aids to Communication

- Allow time for people with aphasia to speak
- Don’t cut off, but do help fill in ideas to assist and confirm understanding
- Look for “back doors” to aphasia (music, art, pictures, emotional triggers)
- Look at context and emotional content of statements, not details of words
- Always validate feelings
“Saving Face”

- Asking for info can be frustrating and fatiguing
- Practice the “fine art of asking questions”
- Help fill in gaps while conversing
- “Speak like a sports reporter”
- Recall an event and let elder add as able
- Don’t diminish person’s recollection
- Preserve dignity in social situations
Working at Tasks

Doing *For*

Vs.

Doing *With*
Tasks

- Approach from the front
- Use “face-to-face communication skills
- Make a connection
- Use name and/or light touch to focus attention
- Prepare and explain, verbal and visual cues as needed
- Check for understanding and acceptance
Tasks (cont.)

- Present objects in proper orientation and ready for use
- Begin with verbal cue
- Add visual if needed
- May need help with:
  - Initiation
  - Sequencing
  - Problem solving
- Hand-under-hand technique
  - Re-awakens “muscle memory”
  - Ensures gentle approach
Wording for Choices

- Open-ended question – when to use?
- Offer a list
- Offer choices two-at-a-time
- Simplify wording and add emphasis and visual cues
- Offer choices one-at-a-time
- Look for non-verbal acceptance or dismissal
- Re-frame “refusals” and “resistance” as *exercising choice*
- “How do they teach us??”
Appreciation and Self-Esteem

- “Can you please help me with this?”
- “Would you please hold this for me?”
- “What do you think about this?”
- Check for direction through steps of a task
- Give positive feedback and compliment (honestly)
- Give thanks and appreciation
- When all else fails, engage through every task
Experiential Approach to Decoding Distress

Dementia is a condition in which a person’s ability to maintain her/his well-being becomes compromised.
General Approach

- Medical Audit (not always necessary)
- Environmental Audit
- *Experiential Audit*
Experiential Audit

- Distress as unmet needs
- Life history, job, hobbies, activity patterns…
- Role play, see through his / her eyes
- Look for meaning in behavioral expression
- Look at well-being domains
Experiential Audit: Preparation

Jane Verity’s *Spark of Life* steps:

- **Shift your focus**
  *Begins with a concerted effort to move from our own perspective and see the world through the eyes of another*

- **Share your heart**
  *Look into the heart of another, without judgment*

- **Shine your light**
  *Use your insights to find the unmet need or environmental mismatch*
Experiential Audit
Using Well-being Domains

- **Identity** *(Is my story known and understood by my care partners?)*
- **Security** *(Do I feel safe in my surroundings and do I trust those who provide my care?)*
- **Connectedness** *(Do I know my care partners? Do I feel like I belong in my living space?)*
- **Autonomy** *(Do I have opportunities for choice and control throughout the day?)*
- **Meaning** *(Are the daily activities meaningful to me? Are my self-esteem and ability to care for others supported?)*
- **Growth** *(Do I have opportunities to experience life in all its variety and to engage creatively with the world?)*
- **Joy** *(Is life celebrated with me? Am I loved?)*
Filling the Glasses
Approach to Distress

- Consider distress to be legitimate, don’t trivialize or challenge,
  *(his/her reality is the one that counts!)*
- Approach alone, calm, centred
- Caring demeanor – voice, face, body language
- Begin by *validating* emotion
- Words won’t be heard till there is an emotional connection
- Move conversation to a less emotional place
- To re-orient or not??
- Investigate triggers
Finding the Calm Center

- Deep breaths
- The slow count
- Imagery
- Look for positive attributes
- Look for positive connections
- Mindfulness practices
- Personal practices (meditation, tai chi, yoga, biofeedback, etc.)
Two kinds of risk:

- **Downside Risk**—The risk that things will turn out worse than anticipated
- **Upside Risk**—The risk that things will turn out better than expected

*Long-term care tends to focus almost exclusively on downside risk*
The “Seesaw Effect”

- We can reduce our downside risk by increasing safety, *BUT* …
- As we increase safety, we also tend to reduce the potential for upside outcomes
- Therefore, improving quality of life involves accepting some degree of risk
- Instead of trying to *eliminate* risk, we must *negotiate* risk
Bill Thomas, MD

“The only risk-free human environment is a coffin.”
Negotiating Risk

- Knowing the person
- Individualizing according to personal values
- Understanding perspectives of family, staff, regulators
- Documenting discussions
- Keep decisions based on principles and values
- Tie decisions in to domains of well-being
“Failure-Free is Not an Option!”

- Success, failure and meaning
- A story from Tennessee

- The most dangerous situation for people living with dementia may well be the self-fulfilling prophecy!
Thank you! Questions?
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