Dementia Beyond Drugs:
Changing the Culture of Care

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Opening Exercise

If a time should come when you could not speak for yourself, what are 2-3 important things that you would want others to know about you?

Perspectives

"The only true voyage of discovery . . . would be not to visit strange lands, but to possess other eyes, to behold the universe through the eyes of another, of a hundred others, to behold the hundred universes that each of them beholds, that each of them is . . ."

- Marcel Proust

U.S. Antipsychotic Prescriptions Since 2000

- U.S. sales, (2000→2014): *$5.4 billion→~$20 billion*
  (#2 drug sold in the US by cost is Abilify: $7.9 billion annual sales)

- Prescriptions, (2000→2014): *29.9 million→~60 million*
  (~2.5 million Americans have schizophrenia)

- 29% of prescriptions dispensed by LTC pharmacies in 2011

- *Overall, 16.1% of **all** people in US nursing homes are taking antipsychotics—down* from (23.9%) at beginning of initiative in 2012. **WA: 15.4% (21st/51), down from 22.3% in 2012.**

- *This still means at least 25% nationwide with a diagnosis of dementia are being given antipsychotic meds (maybe more, due to labelling and "drug diversion").*

Global Perspective on Antipsychotics in Care Homes

- Australia (2010, 2011): ~33%
- NZ (Hawkes Bay 2005, BUPA 2009): residential care—17/15%, private hospital—30/24%, ‘dementia unit’—60/54%
- Survey of care homes in eight European countries (2014): avg. 32% (Range 12% - 54%)
- Canada (1993-2002): 35% increase (with a cost increase of 749%!)
- Health Quality Ontario (2015): 28.8% (Range 0% – 67.2%)
- Worldwide, in most industrialized nations, with a diagnosis of dementia: ~30%

BUT…
Antipsychotic overuse is not only a nursing home problem!

- Nursing home data can be tracked, so they get all the attention
- Limited data suggests the magnitude of the problem may be even greater in the community
  - HHS report: 14% of 1 million community-based Medicare beneficiaries
- If 70-80% of adults living with dementia are outside of care homes, there are probably *over 500,000 Americans with dementia* taking antipsychotics in the community (vs. ~250,000 in nursing homes)
- This pattern is likely true in other industrialized countries as well
- Our approach to dementia reflects more **universal *societal* attitudes**

Personal Expressions in Dementia Do Drugs Work?

- Studies show that, *at best*, fewer than 1 in 5 people show improvement

  Karlawish, J (2006). NEJM 355(15), 1604-1606.

- Virtually all positive studies have been sponsored by the companies making the pills
- Many flaws in published studies
- Four independent studies showed little or no benefit

  Sink et al. (2005), JAMA 293(5): 596-608; Schneider et al. (2006), NEJM 355(15): 1525-1538. Rosenheck, et al. (2007), *Arch Gen Psych* 64(11), 1259-1268.

Risks of antipsychotic drugs

- Sedation, lethargy
- Gait disturbance, falls
- Rigidity and other movement disorders
- Constipation, poor intake
- Weight gain
- Elevated blood sugar
- Increased risk of pneumonia
- Increased risk of stroke
- **Ballard et al. (2009): *Double* mortality rate. At least 18 studies now show increased mortality, (avg. increase ~60-70%)** *Lancet Neurology 8(2): 152-157*

The Last Words?

1) Antipsychotics are largely ineffective and dangerous
2) In fact, there is no chemical rationale for using antipsychotics other than sedation

BUT…

Antipsychotics are *not* the problem!

*The **real** problem is the notion that people need a pill!*

The “Pill Paradigm”

- This comes from deep-seated societal patterns and beliefs:
  - Stigma
  - Ageism and able-ism
  - Desire for the “quick fix”
  - Relentless marketing of pharmaceuticals as the answer to our needs
- . . . All fueled by a **narrow biomedical view of dementia**

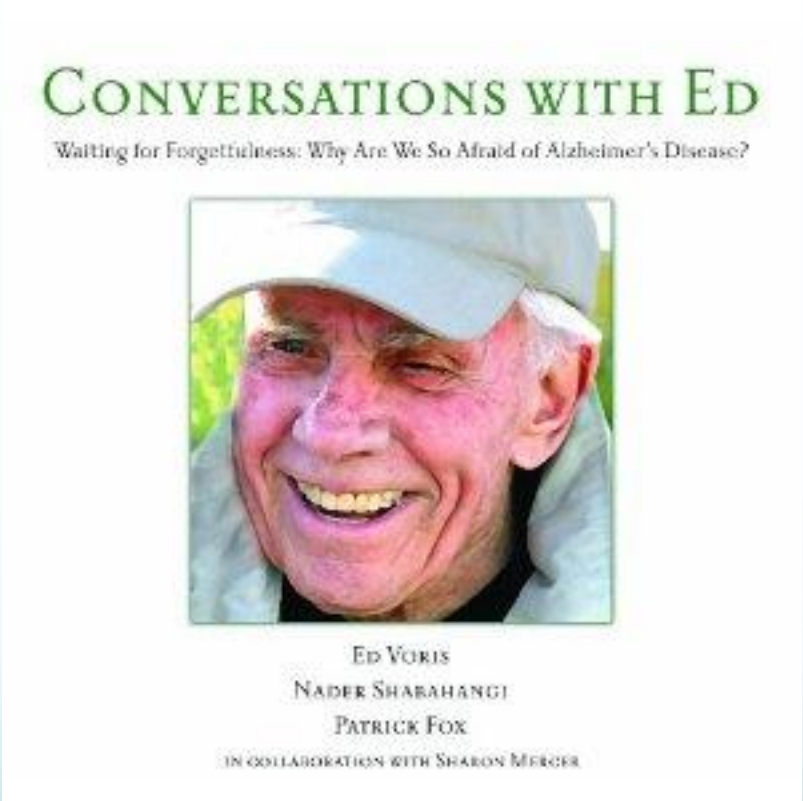
The Biomedical Model of Dementia

- Described as a group of degenerative diseases of the brain
- Viewed as mostly progressive, incurable
- Focused on loss, deficit-based
- Policy heavily focused on the costs and burdens of care
- Most funds directed at drug research

Biomedical “Fallout”…

- Looks almost exclusively to drug therapy to provide well-being
- Research largely ignores the subjective experience of the person living with the disease
- Quick to stigmatize (“The long goodbye”, “fading away”)
- Quick to disempower individuals
- Creates institutional, disease-based approaches to care
- Sees distress primarily as a manifestation of disease (“BPSD”)

Illustrative Example:



Biggest Danger of Stigma → Self-Fulfilling Prophecies

Kate Swaffer

"Upon diagnosis I was Prescribed Disengagement™ from my pre-diagnosis life, which the health care system currently still supports. This sets up a chain reaction of hopelessness and fear, and is the beginning of learned helplessness, which negatively impacts a person's ability to be positive, resilient and proactive, intimately affecting their perception of well-being and quality of life."

The Problem with BPSD

- Relegates people's expressions to brain disease
- Ignores relational, environmental, and historical factors
- Pathologizes normal expressions
- Uses flawed systems of categorization
- Creates a slippery slope to drug use
- Does not explain how drug use has been successfully eliminated in many aged care homes
- Misapplies psychiatric labels, such as psychosis, delusions and hallucinations
- Has led to inappropriate drug approvals in some countries

Personal Expressions May Represent…

- Unmet needs ***/*** Challenges to well-being*****
- Sensory Challenges*****
- New communication pathways*****
- New methods of interpreting and problem solving*****
- Response to physical or relational aspects of environment*****
- May be perfectly normal reactions, considering the circumstances!*****
- May not even represent distress! (“Whose problem is it?”)*****

(*NO medication will help these!)

Shifting Paradigms

How would ***you*** respond if you were told:

- "90% of people living with dementia will experience a BPSD during the course of their illness."

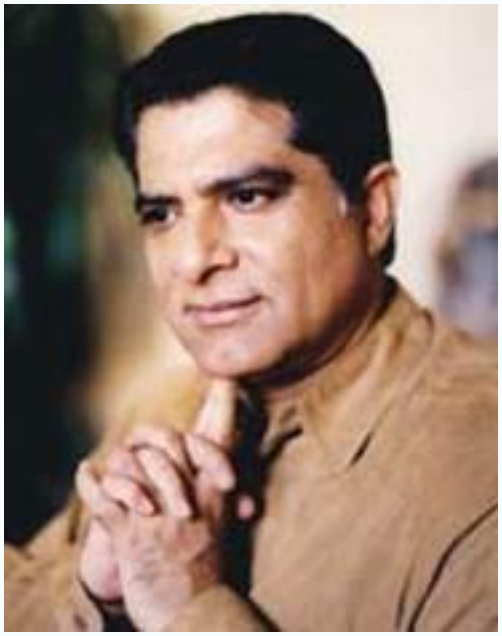
vs

- "90% of people living will dementia will find themselves in a situation in which their well-being is not adequately supported."

So…
Why Do We Follow this Model??

- Are we bad people?? ***No!***
- Are we lazy? ***No!***
- Are we stupid? ***No!***
- Are we uncaring? ***No!***

- Do we have a paradigm for viewing dementia? ***Yes!!***



“Instead of thinking outside the box, get rid of the box.”

A New Model
(Inspired by the True Experts…)









A New Definition

"Dementia is a shift in the way a person experiences the world around her/him."

Where This “Road” Leads…

- From fatal disease to changing abilities
- The subjective experience is critical!
- From psychotropic medications to “ramps”
- A path to continued growth
- An acceptance of the “new normal”
- A directive to help fulfill universal human needs
- A challenge to our interpretations of distress
- A challenge to many of our long-accepted care practices

In Other Words:

Everything changes!

A New Primary Goal:
Create **Well-being**

Question:

*What gives **you***
a sense of well-being?



One Framework for Viewing Well-being

- **Identity**
- **Connectedness**
- **Security**
- **Autonomy**
- **Meaning**
- **Growth**
- **Joy**

Adapted from Fox, et al. (2005 white paper),
now “The Eden Alternative Domains of Well-Being™”

Benefits of Focusing on Well-Being

- Sees the illness in the context of the whole person
- Destigmatizes personal expressions
- Understands the power of the relational, historical, and environmental contexts
- Focuses on achievable, life-affirming goals
- Brings important new insights
- Helps *eliminate* antipsychotic drug use
- Is proactive and strengths-based

Suggested Ordering of Well-Being Domains

Figure 2. The well-being pyramid illustrates the hierarchy of domains to be addressed for restoring well-being. (From *Dementia Beyond Disease: Enhancing Well-Being*, by G. Allen Power. Published by Health Professions Press. Copyright (c) 2014 by Health Professions Press, Inc. All rights reserved. Reprinted by permission.)

A question (or two) for you…

- *What if most of the hard-to-decipher distress that we see is actually related to the erosion of one or more aspects of the person's well-being??*
- Well-being is a need that transcends all ages, abilities, and cultures, and yet…
- There is ***no*** professional training program that teaches about well-being and how to operationalize it…
- *So… is it any surprise that people we care for have ongoing distress, even though we have "done everything we can think of" to solve it???*

For example…

- Addressing physical resistance during bathing becomes more than simply adjusting our bathing technique.
- It involves ongoing, 24/7 restoration of well-being, especially autonomy, security, and connectedness
- These domains of well-being must be not only be appreciated, but actively *operationalized* throughout daily life
- This requires a transformative approach to support and care in all living environments (i.e., “culture change”)

So what does this have to do with “culture change”??

Everything!!

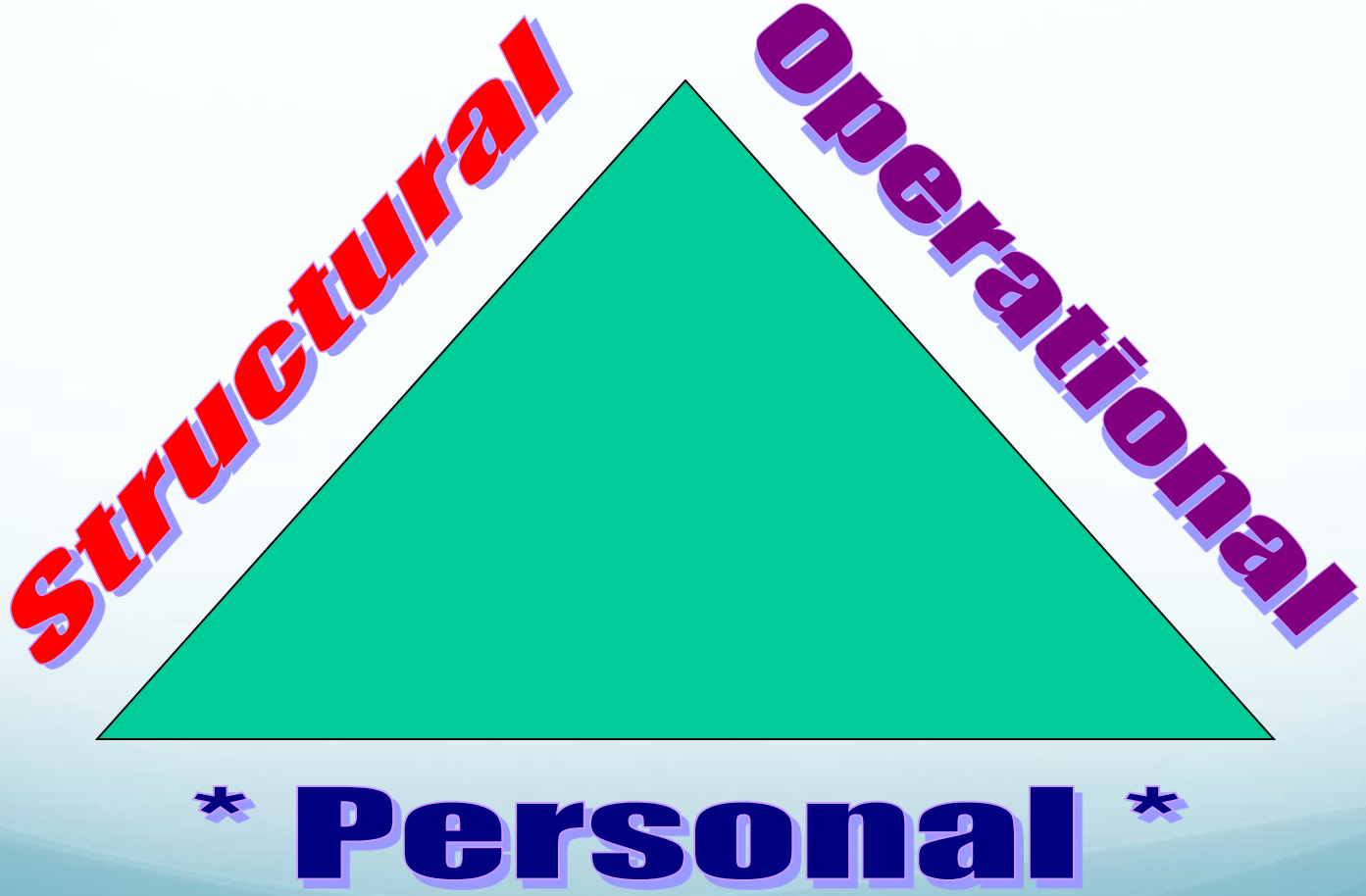
Why it matters

- No matter what new philosophy of care we embrace, if you bring it into an institution, the institution will kill it, every time!

- We need a pathway to *operationalize* the philosophy—to ingrain it into the fabric of our daily processes, policies and procedures.

- That pathway is *culture change*.

Transformational Models of Care



Transformation

- **Personal**: Both *intra-personal* (how we see people living with dementia) and *inter-personal* (how we interact with and support them).
- **Physical:** Living environments that support the values of home and support the domains of well-being.
- **Operational:** How decisions are made that affect the elders, fostering empowerment, how communication occurs and conflict is resolved, creation of care partnerships, job descriptions and performance measures, etc., etc.

Checking the Cows
Why "Nonpharmacological Interventions" Don't Work!

The typical "nonpharmacological intervention" is an attempt to provide person-centered care with a biomedical mindset

- Reactive, not proactive
- Discrete activities, often without underlying meaning for the individual
- Not person-directed
- Not tied into domains of well-being
- Treated like doses of pills
- ***Superimposed upon the usual care environment***

One's own home can be an institution…

- Stigma
- Lack of education
- Lack of community / financial support
- Caregiver stress and burnout
- Inability to flex rhythms to meet individual needs
- Social isolation
- Overmedication in the home

And…
Culture change is for *everyone*!!

- Nursing homes
- Assisted living
- National and State regulators
- Reimbursement mechanisms
- Medical community
- Families and community supports
- Liability insurers
- Etc., etc.

A well-being approach can be used for both:

- Ongoing support and care, and
- Decoding distress

People who wonder whether the glass is half empty or half full miss the point. The glass is refillable.

Filling the Glasses

The Key…

Turn your backs on the "behavior," and find the "ramps" to well-being!

“Dementia Beyond Drugs” 2-Day training

- Full course (administered by The Eden Alternative) has been taught in 7 countries, to a total of ~3000 people (many half-day and full-day seminars have been taught as well)

What is unique about this approach…

- Developed by a physician
- Uses proactive, strengths-based framework
- Incorporates culture change principles necessary to *operationalize* the philosophy

Example 1: CMS Grant for Tennessee Nursing Homes

- 9/2011 – 9/2012: 29.5% → 27.7% (6.1% rel. red.)
- *Dementia Beyond Drugs* course taught to 2-3 employees of each participant home and all surveyors, **12/2012 – 3/2013** on a CMS/DOH grant.
- 9/2012 – 9/2013: 27.7% → 24.0% (**15.4% rel. red.—6th best in the US**)
- CMS grants for KY (2013), MS (2014), OK (2015) and GA/SC/IL/KS/TX (2016)

Example 2: Linden Grove
Waukesha, Wisconsin, US

- 33 staff members, 1 board member and 1 Alz. Assn. representative attended “Dementia Beyond Drugs 2-day training—Summer 2013
- All other staff received 4-hour condensed training from Linden Grove educators
- By September 2014, antipsychotic use dropped **43%:** from 20.5% to 11.7%
- **58%** decrease in documented incidents/episodes of distress
- All residents alarm-free
- Increased staff satisfaction
- Family comments indicate “loved one is back”

Example 3: SAS, Arkansas

- Angie Norman, Arkansas Aging Initiative, UAMS
- Approaches SA and asked or home with 4 highest antipsychotic rates
- Began to work with staff on enhancing well-being domains for all proactively and then shifting systems to support.
- In 8 months, ¾ homes had antipsychotic rate RR of >60%,and increased staff satisfaction.
- Angie: “I believe this proactive approach is the key. It has changed my practice!”

Example 4: Windsor Health Communities

- 10 communities in northern New Jersey (for-profit, mostly old buildings, many double rooms, many on Medicaid, unionized staff)
- **Buckingham at Norwood** community began working with *Dementia Beyond Drugs* approach using book in 2012. Two-day seminar given to clinical and managerial staff in July 2013
- Antipsychotic use dropped **from 33% in 2012 to 0.6% in 2015**
- Several communities also began culture change education concurrently (with Eden guides and with environmental gerontologist Emi Kiyota, PhD)
- Overall antipsychotic use dropped to **6.1%** in homes doing culture change (vs. 15.1% in non-change homes)

How Can Medical Professionals Help?

- Avoid the “knee jerk” prescription
- Stop drugs that are not helping
- Medical evaluation when indicated and redirect approach when it isn’t
- Encourage (and attend, if possible) team meetings to brainstorm better solutions
- In nursing homes, work proactively with DON and consultant pharmacist to drive reduction of antipsychotics and other unnecessary drugs
- Understand and support culture change process (see AMDA 9th function on person-directed care)

Improving Hospitalizations

- Delirium protocols (e.g. HELP)
- Avoid unnecessary or duplicative meds
- Discontinue lines/catheters as soon as able
- Review frequency of VS, BGs, night checks
- Avoid anticholinergics and the one-size-fits-all PRN admission orders
- Early ambulation, quiet nights, minimal moves
- Other initiatives (volunteers, “Getting to Know Me”, etc.)
- **Look at *systems***

True Stories

Looking beyond the words…

Dr. Richard Taylor

“People talk about person-centered care. But if the view of the person doesn't change, then centering on them actually makes it worse.”

Thank you!!
Questions??

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