Dementia Beyond Disease: Enhancing Well-Being

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Disclosures

- I am an Eden Alternative board member (unpaid) and a contracted educator (paid)
- I have books and DVDs
- No other relevant financial interests

Outline

- Review demographics of psychotropic drug use
- Explain drawbacks of the biomedical model of dementia
- Envision an experiential approach
- Well-being as the ultimate outcome
- The culture change connection
- “Why nonpharmacological interventions don’t work”
- Discussion
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→2011): $5.4 billion→$18.2 billion (No. 1 drug sold in the US in 2013 was Abilify: $1.6 billion)

- Prescriptions, (2000→2011): 29.9 million→54 million (~2.2 million Americans have schizophrenia)

- 29% of prescriptions dispensed by LTC pharmacies in 2011

- Overall, ~20% of all people in US nursing homes are taking antipsychotics (~30% with a diagnosis of dementia)

- Medicaid spends more money on antipsychotics than it does on (1) antibiotics or (2) heart medications

Big Secret #1:
Antipsychotic overuse is not an American problem!

- Denmark (2003) – 28%
- Australia (2003) – 28%
- Eastern Austria (2012) – 46%
- Canada (1993-2002) – 35% increase (with a cost increase of 749%)!
- Similar data from other countries (2011 study of >4000 care home residents in 8 European countries→26.4%)
- Worldwide, in most industrialized nations, with a diagnosis of dementia: ~35-40%
Behavioral Expressions in Dementia
Do Drugs Work?

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

- Virtually all positive studies have been sponsored by the companies making the pills.

- Many flaws in published studies.

- Two recent independent studies showed little or no benefit.


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

Big Secret #2: Antipsychotic overuse is not 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.

  - Rhee, et al. (New England, 2011) 17%.

  - Kolanowski, et al. (Southeast US, 2006): 27%.

- 2007 St. John’s audit.

- If 4 out of 5 adults living with dementia are outside of nursing homes, there are probably over 2 million Americans with dementia taking antipsychotics in the community (vs. ~250,000 – 300,000 in nursing homes).

- Our approach to dementia reflects more universal societal attitudes.
A Question for You...

What is Dementia?

The Biomedical Model of Dementia

- Described as a constellation 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
Illustrative Example:

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”
- The end of trying to change a person back to who he/she was
- A directive to help fulfill universal human needs
- A challenge to our biomedical interpretations of distress
- A challenge to many of our long-accepted care practices
In Other Words:

EVERYTHING CHANGES!

Three Views

- “Dad has totally lost it. He thought I was his father instead of his son. He is gone beyond recognition.”
- “If I call you ‘Mom’ or ‘Dad’, I am probably not confusing you with my mom or dad. I know that they are dead. I may be thinking about the feelings and behaviors I associate with mom and dad. I miss those feelings; I need them... I just so closely associate those feelings with my mom and dad that the words I use become interchangeable when I talk about them.” (Richard Taylor)
- “Old people often use an object like a wedding ring to symbolize something from the past. A person in present time, like yourself, can represent a mother or sister. When old people combine one thought with another, they are often poetic.” (Nader Shabahang)

Perspectives...
Does cough syrup cure pneumonia?

Behavioral expressions are the *symptom, not the problem!*

Big Secrets # 3 & 4:

• Our primary goal is *not to reduce antipsychotic drugs!*

• Our primary goal is *not even to reduce distress!!*

Primary Goal: Create Well-being

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

("Wandering " Example...)
Suggested Ordering of Well-Being Domains

MAREP (Ontario, Canada)
Living Life through Leisure Team
- Being Me
- Being With
- Seeking Freedom
- Finding Balance
- Making a Difference
- Growing and Developing
- Having Fun

Leisure – Well-Being Alignment
- Being Me ↔ Identity
- Being With ↔ Connectedness
- Seeking Freedom ↔ Autonomy
- Finding Balance ↔ Security
- Making a Difference ↔ Meaning
- Growing and Developing ↔ Growth
- Having Fun ↔ Joy
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.

Big Secret #5: 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
Transformational Models of Care

Transformation

- 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.
- Personal: Both intra-personal (how we see people living with dementia) and inter-personal (how we interact with and support them).

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
Big Secret #6: Culture change is for everyone!!

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

True Stories

Looking beyond the words...

Questions so far??

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