Living with Dementia: New Perspectives

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Opening Disclaimer

I am on the outside, looking in!

A Few of the True Experts...

Outline

- Quick review of my philosophy
- Drugs, drugs, drugs...Challenging BPSD
- The importance of 'culture change'
- Update on my work with all of the above
- A Modest Proposal (to abolish 'memory care')
- I have a problem with "retrogression"
- 'Open Season'—Q&A

A New Definition

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

Primary Goal: Enhance 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 condition in the context of the whole person
- Destigmatises personal expressions
- Understands the power of the relational, historical, and environmental context
- 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.)

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
- Two recent 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.

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:

Antipsychotic overuse is not only a care home problem!

- Care 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%
  - US-GAO report: 14% of 1 million community-dwelling Medicare beneficiaries
- If 70-80% of adults living with dementia are outside of care homes, there are probably *well over 500,000 Americans with dementia* taking antipsychotics in the community (vs. ~270,000 in nursing homes)
- This pattern is likely true in other industrialised countries as well
- Our approach to dementia reflects more universal *societal* attitudes

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 Worst Application of Stigma??

The Problems with BPSD/NPS

Seeing personal expressions as "symptoms of dementia":

- Ignores relational, environmental, and historical aspects
- Ignores the person's perspective
- Pathologises many "normal" or "expected" expressions
- Promotes a medicalised view of the person
- Creates self-fulfilling prophecies
- **Is a slippery slope to inappropriate psychotropic drug use**

Australia's "21st Century Thalidomide"??

Risperidone (Risperdal):

- Multiple studies worldwide show low efficacy and high risk, including significant increases in **mortality**, stroke, pneumonia, etc.
- US FDA: **No approval** for use in dementia; **"Black box" warning** for same.
- Janssen Pharmaceuticals paid **US$2.5 billion in criminal penalties** for marketing drug to people living with dementia and adolescents.

BUT…

- *Australia has approved risperidone for use in "Dementia with BPSD."*
- **Are Australian brains different from the rest of the world???**

BPSD Algorithms

- Are based on observed expressions
- Suggest various drug or non-drug "Interventions" for the observed 'behaviour'
- Therefore, approach is based on phenomenology, with no regard for individual or relational factors
- **Imagine this: "If short of breath, give a diuretic pill."** (But is it due to heart failure? Or pneumonia, or asthma, or pulmonary fibrosis, or emphysema, or anxiety/ hyperventilation, or simply running up a flight of stairs???)

And…

- How does the BPSD concept explain the many people whose distress is solved without the use of pharmaceuticals?
- How does it account for the ~150 US care homes that have 0% antipsychotic use, and hundreds more with 1-3%?
- What pill can restore identity, connectedness, security, autonomy, meaning, growth, or joy, if they are eroded?

Is There a Dementia Component?

- Yes. Dementia can affect one's ability to:
  - Cope with stressors
  - Remember the information needed to solve challenges and remain in control
  - Use language effectively
  - Creates alternate pathways of communication that may not be well understood by carers
- **But it's not the cause!**

Perspectives

- *'If the care environment is focused on the person and their needs, none of the so-called "challenging behaviour" needs to happen.'* ~Christine Bryden
- *'An abnormal response to an abnormal situation is normal behaviour.'* ~Viktor Frankl
- *'I want my caregivers to know that I don't want to swallow a bitter pill twice a day, nor do I want to be the bitter pill that my caregivers must swallow each day.'* ~Richard Taylor

Shifting Paradigms

- **Usual quote (in media and journals):** *'About 90% of people with dementia will experience a BPSD during the course of their illness.'*
- **Alternate view:** *'About 90% of people living with dementia will eventually find themselves in a situation where their care environment does not adequately support their well-being.'*
- **Each view leads to an entirely different response!**

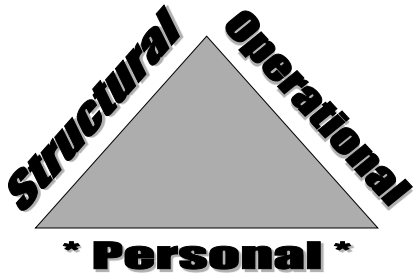
Keep in Mind...

- This is not about bad people!
- It is about systemic and paradigmatic barriers to well-being, similar to what we saw in institutional nursing homes.

Why Culture Change 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 *operationalise* 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, negotiating risk, job descriptions and performance measures, etc., etc.

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

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 "behaviour," 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 ~3500 people (many half-day and full-day seminars have been taught as well)

What is unique about this approach…

- Developed by a physician
- Uses a proactive, strengths-based framework
- Incorporates culture change principles necessary to *operationalise* 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 SNF 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**)
- Federal "CMP" grants for KY (2013), MS (2014), OK (2015) and GA/SC/IL/KS/ and 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: Windsor Health Communities

- 10 communities in northern New Jersey (for-profit, mostly old buildings, many double rooms, many on Medicaid, unionised 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)

True Stories...

Kidbrooke Place, Hermanus, South Africa




The Elephant in the Room...

The Elephant in the Room...

If *dementia-friendly* is defined as creating communities that enable inclusion, regardless of cognitive ability,

Then **aged care**, by definition, is the one sector that continues to be increasingly *dementia-unfriendly*!

Is This the Biggest Misconception in Aged Care??

- Over **100** forms of dementia
- Many levels of ability
- Many variations
- Many histories, strengths, coping skills
- Many cultures
- Over 35 million people worldwide

but…

"One size fits all" housing and care???

Questions

- If you were diagnosed with a form of dementia, would you want to live the rest of your life in a place that only has other people with dementia living there?
- Would you ever want to live in:
  - The Home for People with High Blood Pressure?
  - The Home for Former Care Home Administrators?
  - The Home for a Certain Race, Religion, Ethnicity?
  - The Home for People with Blue Eyes?
- Would any such place treat you like more, or less of a unique individual?
- Do you think that having segregated living makes other elders' and families' fear and stigma greater or less?

Arguments against Segregation:

- Civil rights
- Individualised care
- Clinical
- Relational
- Operational
- Demographic
- Workforce projections
- Stigma
- And more civil rights…

And let me repeat…

- This is not about bad people!
- It is about systemic and paradigmatic barriers to well-being, similar to what we saw in institutional nursing homes.

I Have a Problem with "Retrogression"…

To *'Feel'* vs. to *'Be'*

Dr. Richard Taylor

"I believe that as people progress with dementia, their humanity ***increases.****"*

Thank you!
Questions/Comments?

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