DEMENTIA BEYOND DISEASE: *ENHANCING WELL-BEING*

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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 from June 2014-June 2015 was Abilify (aripiprazole): US$7.2B*
- Prescriptions, (2000→2014): *29.9 million→~60 million (~2.5 million Americans have schizophrenia)*
- 29% of prescriptions dispensed by long-term care pharmacies in 2011
- *Overall, 15.5% of **all** people in US care homes are taking antipsychotics—down* from 23.9% at beginning of initiative in 2012.
- *This still means nearly 25% 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%)
- Health Quality Ontario (2015): 28.8% (Range 0% – 67.2%)
- Denmark 2011: Significant overall decrease, but *large* increase in quetiapine usage, especially if <65 or >95
- Worldwide, in most industrialised nations, with a diagnosis of dementia: ~25-35%

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 problem may be even greater in the community (US-HHS report: 14% of 1 million community-dwelling Medicare beneficiaries with dementia)
- If 70-80% of adults living with dementia are outside of nursing homes, there are probably *over 500,000 Americans with dementia* taking antipsychotics in the community (vs. ~220,000 in US 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, including DLB

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 condition
- Quick to stigmatise ("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")

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
- Pathologises normal expressions
- Uses flawed systems of categorisation
- Creates a slippery slope to drug use
- Does not explain how drug use has been successfully eliminated in many nursing 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!*
- Expressions that threaten one's dignity and personhood*

(*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.'

A NEW MODEL

(INSPIRED BY THE 'TRUE EXPERTS'…)

A NEW APPROACH RESTS UPON THREE PILLARS

- 'Experiential model of dementia'
- Well-being as a primary outcome
- Transformation of the living/care environment

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:
ENHANCE **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
- 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*

HELPING RESTORE WELL-BEING FOR PEOPLE LIVING WITH DEMENTIA

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 S. Allen Power. Published by Health Professions Press. Copyright (c) 2014 by Health Professions Press, Inc. All rights reserved. Reprinted by permission.)

THE 'PUNCHLINE'…

- *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 operationalise 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 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 *operationalised* throughout daily life
- This requires a transformative approach to support and care in all living environments (i.e., "culture change")

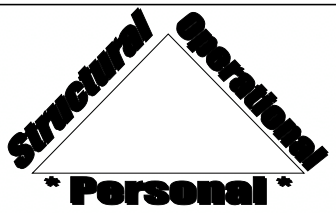
SO WHAT DOES THIS HAVE TO DO WITH 'CULTURE CHANGE'??

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 *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 people with dementia, 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-centred 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
- Care partner 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
- Home and community-based living
- National and Provincial regulators
- Reimbursement mechanisms
- Medical community
- Families and community supports
- Liability insurers, etc., etc.

OPERATIONALISING DOMAINS OF WELL-BEING: A FEW SIMPLE (AND NOT-SO-SIMPLE) EXAMPLES…

EXAMPLE: IDENTITY

"Sundowning," "Elopement," and natural rhythms and activity patterns

OPERATIONALISING WELL-BEING A FEW MORE EXAMPLES

- Preferred name, Evolving and bridging identity, Move-in process (Identity)
- Knocking, Alarm removal (Security)
- Continual consent (Autonomy)
- Rituals (Meaning, Growth, and Joy)
- Opportunities to care and share wisdom, Volunteerism (Meaning, Growth)
- Simple Pleasures (Joy)

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 ~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 *operationalise* the philosophy

EXAMPLE 1: 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 (13-14 months), 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 2: SAS CARE HOMES, ARKANSAS

- Angie Norman, NP, Arkansas Ageing Initiative, UAMS
- Approached SAS and asked for 4 homes with highest antipsychotic rates
- Began to work with staff on enhancing well-being domains for all residents proactively and then shifting systems to support.
- In ~6 months, 3 out of 4 homes had a relative reduction of their antipsychotic rate of **>60%,** and increased staff satisfaction.
- State regulatory and quality organisations want Angie to replicate the model across the state.
- Angie: "I believe this proactive approach is the key. It has changed my practice!"

EXAMPLE 3: WINDSOR HEALTHCARE 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 to 0% since 2016**
- Several communities also began culture change education concurrently (with Eden guides and with environmental gerontologist Emi Kiyota, PhD)
- As of 2016, overall antipsychotic use dropped to **6.1%** in homes doing culture change (vs. 15.1% in non-change homes)

DR. RICHARD TAYLOR

"People talk about person-centred 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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