

Balancing Autonomy and Risk

A Relational Approach

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RESEARCH

EDUCATION

PRACTICE

Enhancing the quality of life and care of older adults through partnerships in *research*, *education* and *practice*.

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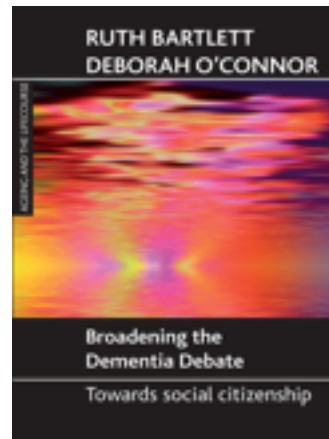
Schlegel Centre for Learning, Research
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Enhancing Life

Remarkable Quote #1

“Oppressive and discriminatory practices often have their foothold in the well-meaning, well-intentioned ideas of those least intending to do harm.”

Bartlett & O’Connor (2010)



Remarkable Quote #2

“Much of what we call ‘person-centred care’ is simply bossing people around in a very individualised way.”

Daniella Greenwood
Strategy and Innovation Manager
Arcare Australia



“AI 101”



My Approach Rests upon Three Pillars

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

Autonomy (Fox, et al. 2005)

- Freedom of choice
- Self-determination
- Self-governance
- Liberty
- Immunity from the arbitrary exercise of authority

Suggested Hierarchy 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.)

Points of Contact

- Autonomy → Identity and Connectedness
- Autonomy → Security
- Autonomy → Meaning and Growth

How well-meaning people can erode autonomy (I/C):

- Stigma and low expectations
- Staging systems, assessments and categorisations
- Communication and care practises
- Care systems and staffing patterns
- BPSD
- Segregated living environments

Assessments (Sabat, 2001)

What is valued by society?

- Experiencing pride, maintaining dignity
- Concern for others
- Communicating feelings
- Maintaining self-esteem
- Spiritual awareness

Even though these are often well maintained in people living with advanced cognitive changes, they are *absent* in cognitive assessments!

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 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 with dementia will find themselves in a situation in which their well-being is not adequately supported.”

How Segregation Erodes Autonomy

- Locked doors
- Lack of choice in determining where to live
- Lack of individualisation
- Lack of contact with more able 'social personae' (Sabat)
- Stigma and low expectations → Self-fulfilling prophecies

Security and Autonomy

- Fragile dynamic (can enhance or inhibit)



- Two common practises that erode autonomy:
 - All-or-none thinking
 - Surplus safety

All-or-None Thinking

- Stems from:
 - Stigma
 - Inability to see nuances of ability
 - Misunderstanding of carer role
 - Misunderstanding of empowerment
 - Inflexible care systems

Surplus Safety



Excessive concern with *downside risk*, relative to *upside risk*

- *Downside risk*: The chance that something will turn out **worse** than expected
- *Upside risk*: The chance that something will turn out **better** than expected
- With dementia, nearly all of the focus is on **downside risk**



Remarkable Quote #3



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

-Bill Thomas, MD

Supporting Autonomy

- Shift to *Relational Autonomy*
- Optimise communication and facilitation skills
- Consider a spectrum of ability
- Look at upside as well as downside
- *Negotiate* risk

Relational Autonomy



- Deep knowing and trust are key
- Partnership approach, supported decision-making
- Implications for dedicated assignments

Relational Autonomy Example: 'Mark and The Lawn Mower'



Brenda Roberts (www.truecolorsofdementia.com)

Optimising Relational Skills

Strong communication and facilitation skills constitute the most basic level of empowerment!

- Understand communication barriers
- Understand shifts to emotion-based expression
- Understand embodiment and other expressions of choice
- Work together through tasks
- Use 'continual consent' and solicit frequent input

7 Steps to Negotiating Risk

(Power, 2014)

- Discussion
- Exploration of values, tie-in to well-being
- Conditions of empowerment
- Continuum of empowerment
- Collaborative decision
- Documentation and monitoring of results
- Keeping other stakeholders abreast of the process

Example: How Risk/Reward Values Vary

(Courtesy Daniella Greenwood, Arcare Aged Care)

Joan



Harry



Example of Negotiating Risk: 'Fred and the Locked Door'



Heather Luth

Dementia Program Coordinator,
Schlegel Villages, Ontario, Canada



Poll Question #1

*What would **you** do next?*

- 1) Change door code, revoke privileges
- 1) Change code, outside only when accompanied
- 1) Continue present plan +/- minor modification
- 1) Other / not sure

Poll Question #2

*What do you think **your organisation** would do?*

- 1) Change door code, revoke privileges
- 1) Change code, outside only when accompanied
- 1) Continue present plan +/- minor modification
- 1) Other / not sure

Autonomy and Meaning/Growth: A Story from Tennessee



And What about Downside Risk??

- Downside risk is real
- Start with relationships
- Use incremental steps to minimise downside, achieve early victories, and enable cumulative organisational shifts
- *Ask: What is the downside risk of **not** doing it??*

‘An injury or death after leaving a building is a serious event, and would likely be reported all over the news. The gravity of such outcomes is not to be minimised.

‘But for every person who actually suffers such a fate, how many people on a daily basis are forced to live with anxiety, fear, and life-giving needs that remain unmet? Or withdraw and give up on life, as many prisoners of war have done? Or become overmedicated with dangerous and sedating drugs as a result of their distress? Hundreds? Thousands?

‘These are also very newsworthy negative outcomes that will start to be more widely publicised as consumer awareness grows...

We must always negotiate risk, balancing it against the ability to live life to the fullest extent possible.’

<http://changingaging.org/dementia/the-hidden-restraint-part-4/>

One last quote to consider:

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

Thank you!

Questions?



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