Dignity and the role of stigma in dementia

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An Applied Practice-based Dementia Care Research Network

- INTERDEM – International
- Groups of Research ‘clinicians’/practitioners with shared sub-interests in applied dementia ‘care’ psychosocial research
- Truly multidisciplinary
- Collaborative research across nations
- Over 170 members across about 20 European Nations with Australian and US honorary members.
- Asian-Pacific sister organisation PROMOTE
- Members must be actively engaged in dementia care research in centres that have funded research activity in their own country
Stigma

Stigma causes an individual to be perceived by others in an undesirable, rejected stereotype rather than an accepted normal one.

The stigma attached to dementia reduces the person with dementia to a person who is unable to maintain social relationships and activities.
Dementia Elevator - General Awareness Video

http://youtu.be/V90CFkiUozE
Impact stigma

Societal discrediting adds to the hardship of persons with dementia

Stigma ignores the capacities of the person and is a serious threat to their feelings of dignity
Dignity key feature in dementia care

Loss of dignity causes suffering, but maintaining dignity considerably contributes to a better quality of life.

Dignity can be restored
Dignity: concept and measurement

Importance not being considered as a burden to others as well as continuing to be useful erberg, Lepp e.a., J Adv Nursing, 2007)

Measurement: Patient Dignity Inventory (Chochinov e.a. , J Pain Symptom Man, 2008)
How to influence dignity?

Acknowledge the capacity of the person with dementia to contribute to family and society (REciprocity)
Citizen: reciprocity

Capacity to give something back in return for receiving (Gouldner, 1960)

Desire to give in palliative patients (Osse, Vernooij-Dassen et al. Support Care Cancer, 2005)

Desire to give in persons with dementia (Gove, 2013)

(Vernooij-Dassen, Leatherman, Olde Rikkert, BMJ, 2011)
Side effect of care

Challenge to reciprocate

Support can threaten self-esteem

(Vernooij-Dassen, Leatherman, Olde Rikkert, BMJ, 2011)
Autonomy

Desired autonomy: clarity about needs and preferences as well as capacities and restrictions

Desired dependency: clarity about desire to be supported

Balance between direction and dependency

(de Lange, 2004)
Undesired (in)dependency

Fragile balance between direction and dependency
Not knowing how to ask for support
Over- or underestimating capacities

(de Lange, 2004)
Dignity and autonomy

Respecting needs for autonomy

Acknowledge existing capacities and restrictions

(de Lange, 2004)
Dignity and autonomy

“I don’t want someone to do for me, I want to do it myself”

(Henry Rankin, Dementia in Europe, 2014)
Preserving dignity

Don’t:
Offend people with dementia

Do:
Support people with dementia with the same respect you want for yourself
Treat every person as an individual by offering person centered careservices
Enable persons with dementia to maintain maximum possible level of independency, choice and control (S-Australian Healthcare)
(www.kateswaffer.com)
Addressing dignity is neither costly nor time consuming and can make the difference
Hypothesis: READI

RECiprocitiy → Autonomy → Dlignity
Dignity on the agenda

INTERDEM manifesto
The Joint Programme Neurodegenerative Diseases
Australian campaign to preserve dignity in dementia
Alzheimer Europe conference
Achievements: Collaborative Research in Europe: JPND 2013

- Myrra Vernooij-Dassen on Scientific Board – ‘the science of psychosocial care research’
- 3 new INTERDEM led awards:
- Member collaborators:

  MEETINGDEM, Droës

  ACTIFCare: Verhey, de Vugt

  RHAPSODY: Kurz, de Vugt
Interventions considering reciprocity and autonomy

Occupational therapy (Graff, Vernooij-Dassen, Olde Rikkert e.a., BMJ 2006)

Shared decision making (Elwyn, Dehlendorf e.a. Ann Fam Med, 2014; Groen-v.d. Ven, Span M, Vernooij-Dassen M, Smits C et al. submitted)


Dignity and de-stigmatisation

Dignity is acknowledged as a powerful means of improving the quality of persons with dementia
Perceptions of dignity

Individual self (internal)
Relational self (in reciprocal relationships)
Societal self (social object in the eyes of others)

(van Gennip, Pasman, Oosterveld-Vlug, Willems, Onwuteaka-Philipsen, Int J Nursing Studies, 2013)
NEW AVENUES: individual self and self-compassion

Self-compassion entails treating oneself with kindness, recognizing one’s shared humanity and being mindful when considering negative aspects of oneself.

Self-compassion predictor happiness, optimism and positive affect.

Self-compassion useful alternative to global self-esteem
(Neff, Vonk, Journal of Personality, 2009)
Momentum: new policies

Participation society: stimulation of independence and social cohesion

Patient as partner