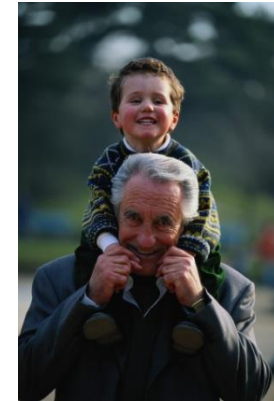




An Australian Government Initiative



WA Dementia Training Study Centre **WADTSC**



Training support • Skills development • Competency • Assessment • Scholarships • Education

Centre for Research on Ageing

Training to care for people with dementia



Issues in Research Measuring Quality of Life & Dementia

Why this topic? **Demonstrate value of research AND one of our greatest challenges**

Why measure QOL? **Ultimate outcome of care - striving to achieve**

Professor Barbara Horner, Curtin University, WA
[Professor Wendy Moyle, Griffith University, QLD
& Dr Chris Beer et al, UWA]



“Yes, it all comes down to quality of life. An inheritance sure would help.”



Quality of life

- The World Health Organisation Quality of Life Group (1993) defines it in this way:

“Quality of life is defined as an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relating to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person’s physical health. Psychological state, level of independence, social relationships, personal beliefs and relationships are salient features of the environment.” (p153)



What does 'Quality of Life' mean?

Yourself?

Your clients?

Feedback....



Approaches and Interpretations

- Linked with subjective well-being & happiness (Bidewell, 2003)
- Absence of biomedical health problems (Elovainio & Kivimäki, 2000)
- Sense of cohesion (Antonovsky, 1987)
- Person/environment fit (Lawton, 1989)
- Domains of QOL (Kane, 1998, 2001)



11 Domains of quality of life (Kane)

- Safety/security
- Physical comfort
- Enjoyment
- Meaningful activity
- Relationships
- Functional capacity
- Dignity
- Individuality
- Privacy
- Autonomy/choice
- Spiritual well-being



Perceptions of quality of life from people living with dementia

- What might 'quality of life' be for someone living with dementia?
- How do we measure quality of life?
 - Ask person (survey, interview)
 - Ask their proxy (survey, interview)
 - Observe (person, documentation analysis, DCM)
- How do we know that they are satisfied with their quality of life?



Measuring quality of life for people with dementia?

- The potential for self-report
 - Reliable
 - Valid
 - May differ from caregiver perspective
- Self-report measures
 - DQOL – (Brod et al, 1999)
 - QOL-AD (Logsdon et al, 1999)
 - DEMQOL (Smith, Banerjee et al 2006)
 - Limitation of pre-defined domains
- Proxy and observational measures useful in severe dementia



QoL and dementia

QOL-AD (Logsdon et al, 1999)

Simple self-report measure of QoL

- 13 items, 4 point scale
- E.g. Energy; Fun; Money; Physical health; Friends; Family etc.
- Completed in interview with person
- Domains validated from focus groups (people with dementia & carers) & questionnaires (professionals)



What does predict quality of life in people with dementia?

- Smith et al 2006 (DEMQOL-Proxy) n=99
 - Behavioural and psychological symptoms (NPI) agitation, depression, anxiety, disinhibition, and irritability
 - Younger age
 - Mental health of carer (univariate only)
- Hoe et al (2005) QOL-AD (combined) severe dementia MMSE 3-12, n=41
 - person's self-care skills
 - fewer physical health limitations
 - positive mood status
 - low levels of apathy



What does predict quality of life in people with dementia? (3)

- Thorgrimsen et al (2003) Self-reported QoL-AD residential homes / day centres (MMSE 14.4 sd 3.8) n=201
 - QOL-AD not correlated with memory and cognition measures such as ADAS-Cog or MMSE
 - *Higher* in those with moderate dementia than in those with mild dementia on clinical dementia rating
 - Relates to depression, not cognition
- Woods et al 2009 – community sample, n=77
 - Self-rated quality of relationship warmth with caregiver predicts QoL (stronger effect than depression)



How can QoL of people with dementia be improved?

- Improve mood
 - E.g. Pleasurable activities, CBT for depression
- Help staff to have more 'hopeful' attitudes (Spector & Orrell, 2006; Lintern & Woods, 2000)
- Enhance relationship with caregiver
- Reduce use of anti-psychotic medication (Fossey et al, 2006)
 - May also require work on reducing behaviour that challenges
 - major issue for caregivers



Enhancing QOL and Moral Care in people with dementia: Moyle, Venturato, McAllister & Oxlade ARC (L) 2007-2010

Snap shot of findings:

- QOL-AD (1 Poor; 2 Fair; 3 Good; 4 Excellent)
 - Resident Mean (SD): 2.62 (0.45);
 - Residents scored ↓ on “Energy” (2.16) & ↑ on “Relationships with staff” (3.26)
 - Nurses Mean (SD): 2.33 (0.57);
 - scored significantly ↓ than residents on ($p < 0.001$): “Relationships with staff”; “Friends”; Ability to care for oneself”; Ability to make choices”
 - Family Mean (SD): 2.34 (0.49);
 - scores significantly lower on ($p < 0.001$): “Ability to take care of oneself” & “Ability to make choices”



Snapshot Qualitative Findings - **Family Interviews**

- Indicate that they are generally satisfied with the level of care
 - *“She gets good care as far as her bedding, food & everything is there for her. If she wants to go out on day trips & that, we can’t complain”*
- Things that **reduced QOL**
 - Too much focus on physical aspects of care
 - *I don’t have a problem with her care. I would like to see her do more, but that is another question....she does nothing other than sit in front of the TV and listen to it”*



Snapshot - Qualitative Findings: **Person with Dementia**

Interviews

- QOL described as being overall good but defined as
 - “.. good as can be expected” & “... having three meals a day and there’s a television to watch sport..” makes life good
 - Life won’t get better “... unless I get better, it wouldn’t be much good” and “I am 88 you can’t have things going smoothly all the time”.
- Things that **reduced QOL**
 - Staff frequently seen as too busy to spend quality time with resident
 - “They seem to have very short staff quite often and the girls really work hard”
 - Need staff to “listen to me and that’s very important to me”



Perspectives of quality of life among people with dementia living in the community and care facilities

Bosboom, P., Jones, G., Banz, K., Almeida, O.P., Flicker, L., Launtenschlager, M.T., Horner, B., Scherer, S., Beer, C.

Although many people with dementia (PWD) can reliably report their quality of life (QoL), use of informants is common.

Determine the influence of resident and informant perspective and place of residence on rating of QoL of PWD.

Methods: 65 healthy older controls, 50 PWD living in the community (PWD-C), 50 PWD living in RAC (PWD-RCF), and their informal carers (informants) participated.

The Quality of Life in Alzheimer's Disease (QOL-AD) scale was used to measure QoL by self and informant reports.

Informants rated QoL from two perspectives: i) their estimation of the person's self-rating ('informant-proxy'), and ii) their opinion of the person's QoL ('informant-opinion').

Scores are reported as a percentage of the score maximum (% Score Max)

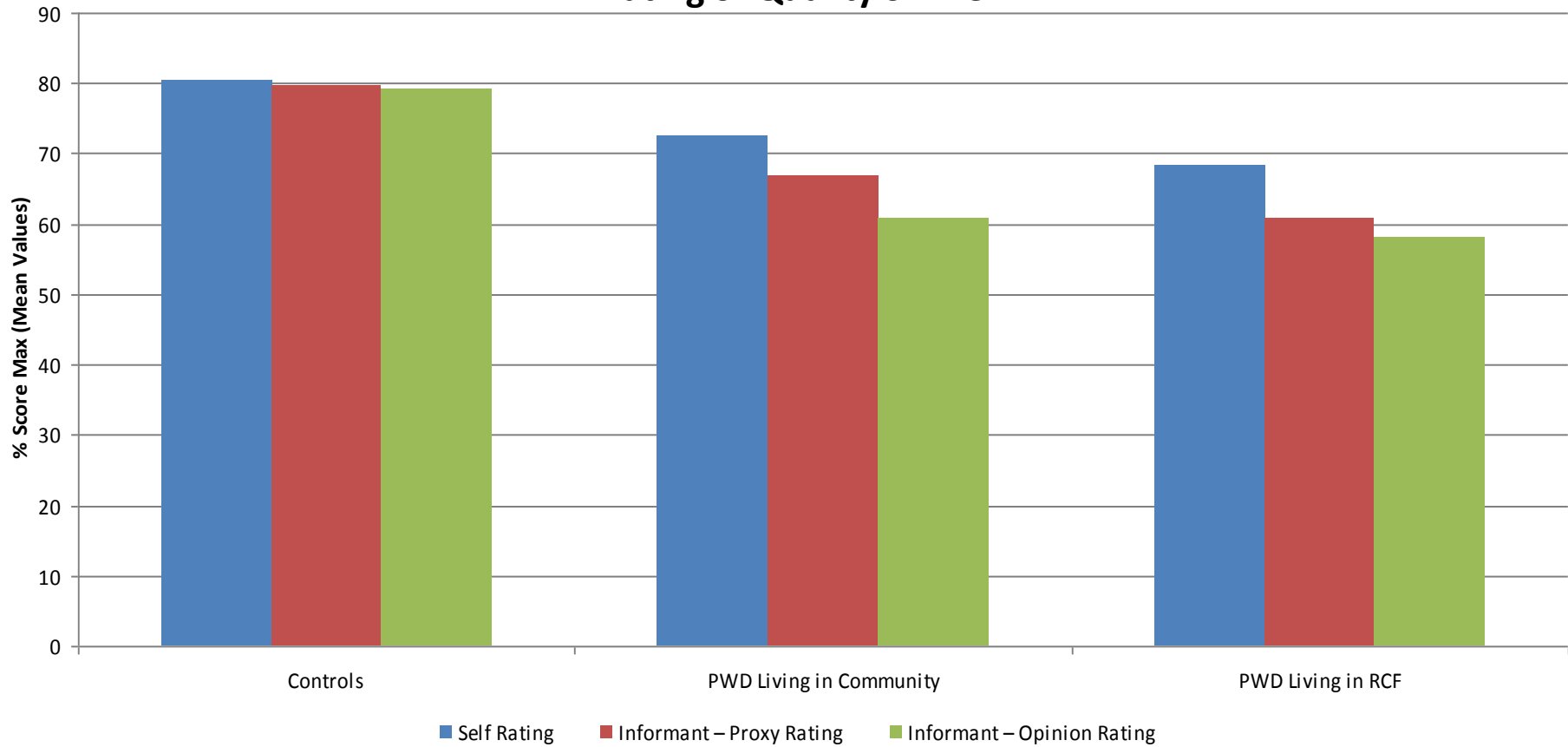
Results: QoL-AD scores in the control group rated by self-report, informant-proxy and informant-opinion reports were comparable

For PWD-C and PWD-RCF the mean self-rated QoL was higher than informant-rated QoL.

Informant-proxy ratings tended to more closely estimate self-rating than informant-opinion. The difference between the informant perspectives was greatest for PWD-C.



Rating of Quality of Life





Assumptions and Cautions

1. What do you want to measure
2. What are you going to do with the results
3. Trial instruments
4. Obtain consent
5. Engage with family
6. Establish good rapport
7. Allow time for assessment
8. Provide a comfortable and private environment
9. Learn from the findings
10. Provide feedback to participants



An Australian Government Initiative

Thank you

Questions and comments