Perspectives of Quality of Life among people with dementia living in the community and care facilities

Data from two WACHA studies:

DIRECT (Dementia in Residential Care: Education Intervention Trial)
QoLCog (QoL and Cognition in Alzheimer's disease)

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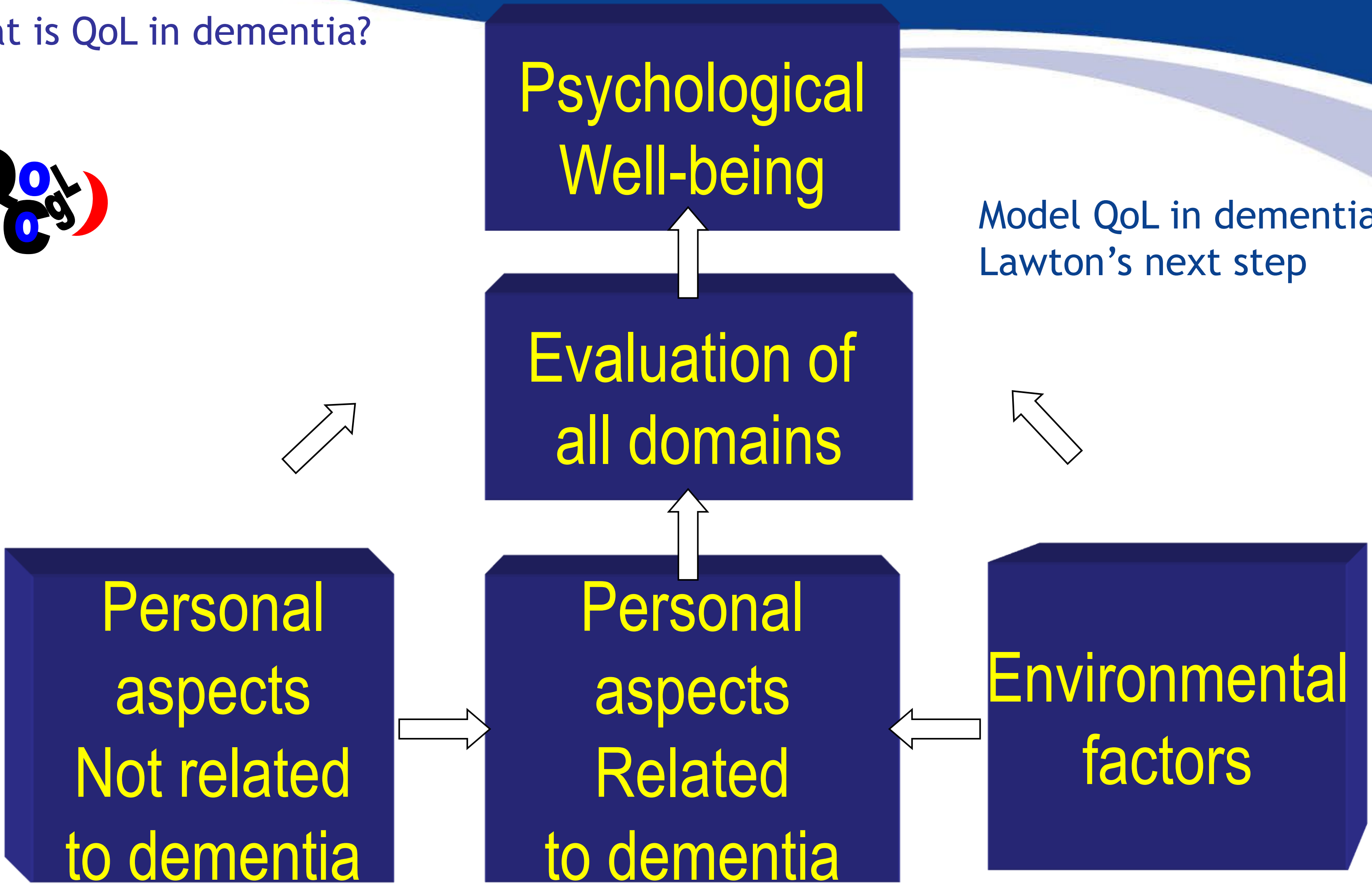
Background

- Without a cure for dementia, improvement of Quality of Life (QoL) should have high priority in care, treatment and research
- QoL can measure whether an intervention has made an important difference
- QoL in dementia is a widely used, but complex concept
- Relevant factors that predict QoL ratings unclear
- Incomplete understanding of QoL and its measurement
- Instruments available to measure disease-specific HRQoL
- Several factors influence choice of tool to measure QoL among PWD

What is QoL in dementia?

QolCog Study
WACHA
UWA Perth

Model QoL in dementia, Lawton's next step



Psychological Well-being

Evaluation of all domains

Personal aspects Not related to dementia

Personal aspects Related to dementia

Environmental factors

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QoL among PWD

- People with dementia frequently experience distressing emotions
- May relate to awareness of deficits, environment and unmet needs [1] [2]
- People with mild to severe dementia can reliably rate their own QoL [3]
- However, use of staff or family carer informant QoL ratings is widespread
- Potential problems with the use of staff informant ratings

1. Clare L, Rowlands J, Bruce E, Surr C, Downs M (2008) The Experience of Living With Dementia in Residential Care: An Interpretative Phenomenological Analysis. Gerontologist 48: 711-720.
2. Clare L, Rowlands J, Bruce E, Surr C, Downs M (2008) `I don't do like I used to do': A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. Social Science & Medicine 66: 2366-2377.
3. Hoe J, Katona C, Roch B, Livingston G (2005) Use of the QOL-AD for measuring quality of life in people with severe dementia--the LASER-AD study. Age Ageing 34: 130-135.

Hypotheses

- Informants do not reliably estimate person’s own assessment of their QOL
- Informant ratings influenced by specific factors, such as the severity of cognitive impairment and place of residence
- For PWD-RCF family carer informant ratings may be more reliable

Aims

(1) Overview of our studies: how can we measure QoL in dementia?

(2) Do PWD and their carers agree when rating QoL?

(3) Is (dis)agreement the same among different groups of PWD?

(4) Does it matter how we ask informants about QoL?

(5) What factors are associated with patients' and carers' QoL-ratings?

(6) Does cognitive impairment influence QoL ratings?

(7) Do these data have practical implications?

QoL-Cog and DIRECT Studies

N= 75 healthy older controls
N= 80 PWD living in the community (PWD-C)

+ their informal carers (informants)

Recruited by the **QoLCog study**, a prospective observational study to determine the association of cognitive decline with QoL in AD over time

QolCog Study
WACHA
UWA Perth

N= 350 PWD living in residential care facilities (PWD-RCF)

+ their informal carers (informants)

Recruited by the **DIRECT study**, an RCT of educational interventions, aiming to improve QOL of PWD living in RCF

DIRECT
Dementia in Residential Care: Education Intervention Trial

QoLCog study - design

- diagnosed with mild-moderate AD or ADmixed
- living in the community
- NoK as informant

- healthy older adults
- living in the community
- NoK as informant

100 AD/ADmixed + informant

80 Controls + informant

Generic and disease specific QoL questionnaires (self-rated & proxy-rated)
- Comprehensive selection of cognitive tests
- Psychological and behavioural symptoms associated with dementia

Baseline study

18-months follow-up

QolCog Study
WACHA
UWA Perth

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QolCog Study
WACHA
UWA Perth

Participation criteria

- Community-dwelling patients with the diagnosis of probable Alzheimer’s disease (AD or ADmixed) of mild/moderate severity according to NINCDS-ADRD criteria, and their carer as informant.
- Family informants for PWD living in community were required to have regular contact with patient with AD for no less than 3x/wk over preceding year up till now.
- Excluded patients with history of alcohol or substance abuse (APA, 1994), and those with medically unstable illness that could compromise survival (such as metastatic cancer).
- Pts with AD could be taking cholinesterase inhibitors or memantine, but could not be participating concurrently in an experimental study of medications for AD. All participants were competent in written and spoken English.

- **Ethics Statement**
- Approved by the Human Research Ethics Committee of the UWA, RPH, Mercy Hospital and Neurosciences Unit.
- For PWD a structured consent procedure was utilized (comprising informed written or verbal consent, as well as the agreement of next of kin).

Participation criteria

- Family informants for PWD living in RCF were required to have visited the PWD on average at least once per week over the previous year.
- Staff informants were required to have known the resident for at least two weeks, and to have observed that resident at least 10 times, or for a minimum of one hour in total, during the previous two weeks.

Ethics Statement

- Approved by the Human Research Ethics Committee of the UWA.
- For PWD a structured consent procedure was utilized (comprising informed written or verbal consent, as well as the agreement of next of kin) and, when severity of dementia precluded the resident from providing consent that was clearly informed, agreement from the resident’s ‘next of kin’.

Participants – demographics

- Controls:
  - Pts 75.1 (SD 6.1; range 56-92), 45.9% women; 62.2% lived with NoK
  - NoK 65.2 (SD 13.7); 82.4% of NoK women
  - 59.5% born in Australia

- PWD-community:
  - Pts 78.3 (SD 7.9; range 56-92), 67.5% women; 75% lived with carer
  - Carers 66.6 (SD 14.5); 57.5% of carers women
  - 52.2% born in Australia

- PWD-RCF: 85.3±7.9 years

Participants - MMSE

- Controls 28.5 (SD 1.6; range 24-30)
- PWD-C 18.5 (SD 5.0; range 7-29; 34.2% mild; 59.5% moderate; 6.3% severe)
- PWD-RCF (N=189) 16.1(SD 5.8; range 0-24; 28.6% mild; 52.9% moderate; 18.5% severe).

Predictor variables

- Date of birth and gender
- Standardised Mini-Mental State Examination
- Controls
- Community dwelling PWD: Neuropsychiatric Inventory (NPI)
- RCF dwelling PWD: Self report and observational measures of pain, restraint, and care

In the CoLCog study, cognitive functions assessed with the following tests:

- CAMCOG-R
- Rey Complex Figure Test (RCFT)
- Visual Association Test (VAT)
- CVLT-II - short version
- NAB Screening Language Module
- D-KEFS Verbal Fluency Test
- D-KEFS Trail Making Test
- WAIS-III Digit Span
- WAIS-III Digit Symbol
- WTAR

BPSD rated according to:

- NPI
- IQCODE
- GRAD
- Starkstein’s Anosognosia Questionnaire
- Katz’ ADL
- Lawton’s IADL
- Hospital Anxiety and Depression Scale (HADS)
- Cognitive Performance Self-rating scales (i.e. pros- and retrospectively)

Exposure	Exposure measure	Source	Score details
Socio demographics of Pt	Age, DOB, sex, marital status, education , living together	Pt + carer	
Diagnosis of Alzheimer’s disease	AD or Admixed	Clinician	
Socio demographics of carer	Age, DOB, sex, relationship with Pt, hours of contact p/wk, living together	Carer	
Burden of care	NPI	Carer	Subscore
Cognitive functioning overall	CAMCOG-R	Pt	Total score
Severity of cognitive dysfunction	MMSE at time of assessment	Pt	Subgroup
Cognitive decline over past 10 yrs	IQCODE	Carer	Average item score
Insight/awareness	GRAD	Pt	Rating by clinician
Anosognosia	Anosognosia Questionnaire Dementia	Carer + Pt	Difference score
Psychopathology	NPI	Carer + Pt	Total score
Anxiety	HADS	Pt	Subscore
Depression	HADS	Pt	Subscore
ADL	Katz’ ADL	Carer	Total score
IADL	Lawton & Brody’s IADL	Carer	Total score
Medication (0. 1-2, 3-4, 5+) and type (Anti-Alzheimer’s drugs; Psychotropics)	Questionnaire	Carer + Pt	

Analyses

Descriptive analysis (means for each group for each method of rating, mean differences)

Mean difference, between **PWD-RCF able to self rate QoL** with, and without, each candidate predictor variable and the respective 95% confidence interval (95%CI) for the difference

Simple linear correlations (calculation of Pearson's correlation with self-rating and comparison of scores)

Bland-Altman plots generated to determine agreement

Linear regression analyses were performed: univariate; parsimonious

1. How can we measure Quality of Life in dementia?

- Many different tools available
- Report v observation
- Self v informant report
- Domains vary

Methods – Measurement of QOL

QoL instrument:

Quality of Life – AD *(QOL-AD, Logsdon et al., 1999; 2002)*

- Primary outcome measure
- Most widely used HR-QoL instrument in dementia
- Self-report by AD Patients

QoL-AD questionnaire (Logsdon et al., 1999, 2002)

Item		Response scale (range 1 – 4)*			
1.	*Physical health*	*poor*	*fair*	*good*	*excellent*
2.	*Energy/vitality*	*poor*	*fair*	*good*	*excellent*
3.	*Mood*	*poor*	*fair*	*good*	*excellent*
4.	*Living situation*	*poor*	*fair*	*good*	*excellent*
5.	*Memory*	*poor*	*fair*	*good*	*excellent*
6.	*Family*	*poor*	*fair*	*good*	*excellent*
7.	*Marriage*	*poor*	*fair*	*good*	*excellent*
8.	*Friends*	*poor*	*fair*	*good*	*excellent*
9.	*Self as a whole*	*poor*	*fair*	*good*	*excellent*
10.	*Ability to do chores*	*poor*	*fair*	*good*	*excellent*
11.	*Ability to do things for fun*	*poor*	*fair*	*good*	*excellent*
12.	*Financial situation*	*poor*	*fair*	*good*	*excellent*
13.	*Life as a whole*	*poor*	*fair*	*good*	*excellent*

* Overall scores = summing the 13 items; total score ranging 13 to 52; higher scores indicating higher QoL.

*Item 7 'Marriage': often not applicable/incomplete; excluded from this analysis

QOL-AD: 15 item version modified for RCF

1	Physical health	9	Self overall
2	Energy	10	Ability to keep busy
3	Mood	11	Ability to do things for fun
4	Living situation	12	Ability to take care of self
5	Memory	13	Life overall
6	Family	14	Ability to live with others
7	Relationships with people who work here	15	Ability to make choices in one’s life
8	Friends		

Logsdon 2002 Edelman 2005 Sloane 2005

Analyses

Because of different number of items, QOL scores reported as a percentage of the score maximum (% Score Max)

Reliability Study

- Recruitment and training of research staff
- Joint administration of the self-rated QOL-AD by two staff until 20 residents had been jointly assessed
- Inter-rater reliability study in which both staff members independently administered the self-rated QOL-AD to a further 20 residents, and then crossed over. The second rater administered the QOL-AD within 24 h of the initial administration of the QOL-AD
- Interviewers used a standard set of instructions
- Participants were handed their own copy of the questionnaire
- Participants were able to indicate responses verbally or by circling the response
- Excluded if unable to respond to more than two items

Results

- Age 87.5 ± 8.1 years (range 77–95)
- Mean MMSE score 15.4 ± 5.2 (range 5–22)
- The mean (SD) QOL-AD scores:
  - R1 42.0 ± 6.4
  - R2 43.3 ± 5.8
- Mean difference in total self-rated score 3.6 ± 3.4 (range 0–11)
- Intraclass correlation 0.68

Reliability

	Agreement , n (%)	Cohen’s Kappa	Linear Weighted Kappa
1. Physical Health	11 (55%)	0.16	0.30
2 Energy	14 (70%)	0.49	0.50
3. Mood	10 (50%)	0.18	0.27
4. Living situation	14 (70%)	0.44	0.41
5. Memory	12 (60%)	0.44	0.59
6. Family	12 (60%)	0.29	0.42
7. Relationships with people who work here	10 (50%)	-0.05	*
8. Friends	12 (60%)	0.15	0.22
9. Self overall	10 (50%)	0	0.16
10. Ability to keep busy	10 (50%)	0.16	0.15
11. Ability to do things for fun	12 (60%)	0.35	0.50
12. Ability to take care of self	10 (50%)	0.02	0.13
13. Life overall	9 (45%)	-0.02	*
14. Ability to live with others	12 (60%)	-0.05	*
15. Ability to make choices in one’s life	14 (70%)	0.33	0.30

*Weighted kappa not calculated. Mean concordance is less than expected by chance.

Reliability -Conclusions

- Good overall reliability indicated by the intraclass correlation coefficient for total QOL-AD scores

- Individual items generally had poor to moderate reliability

  [poor≤0.2, fair 0.21–0.40, moderate 0.41–0.60, good 0.61–0.80 or very good 0.81–1.00]

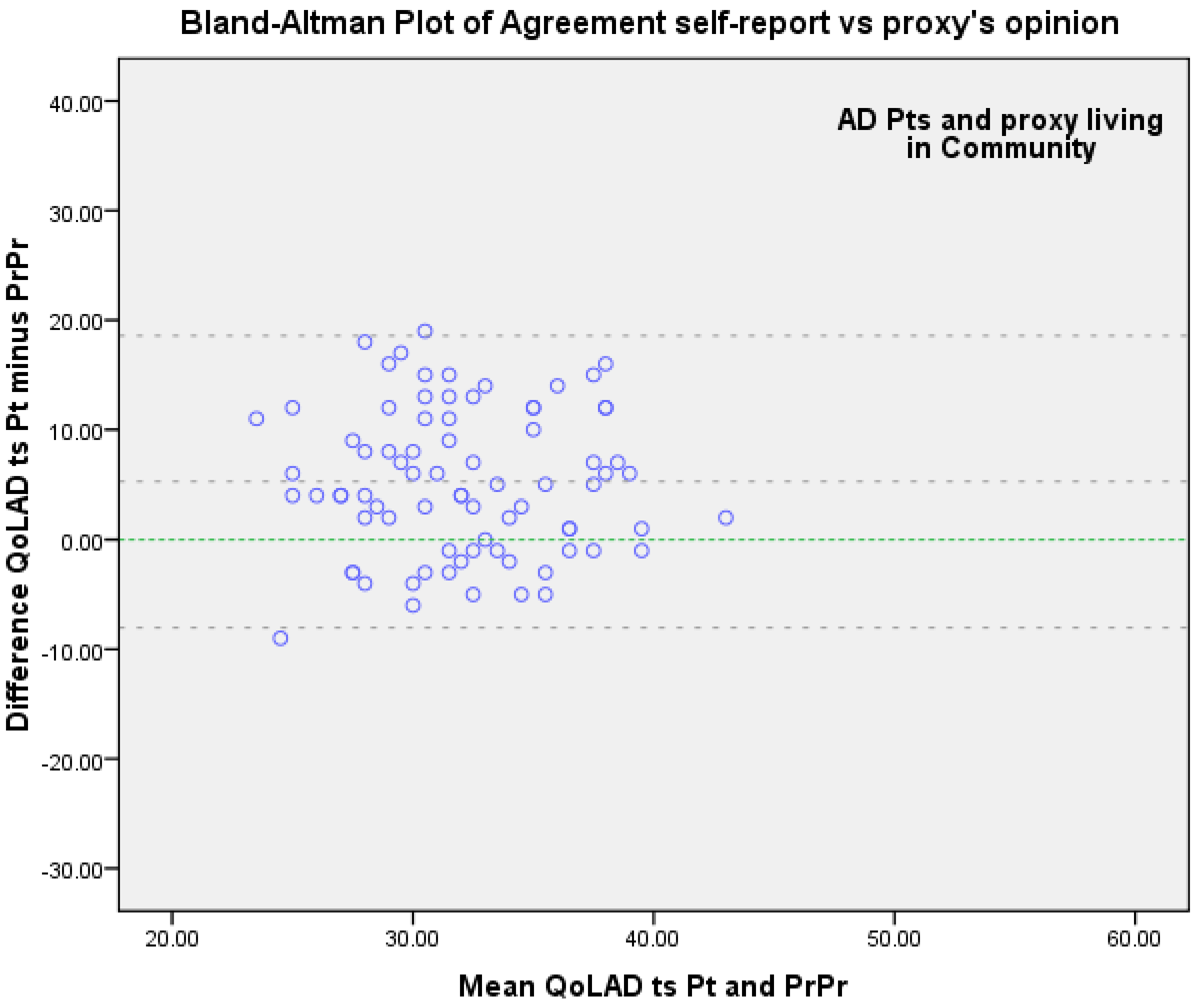
- All items with poor reliability were items that have been modified for use in RCF

Beer C, Bosboom P, Almeida OP, Flicker L. Rating the quality of life of people with dementia living in residential care facilities in routine research practice. Age and Ageing 2009; 38(3):343-6

Self rating among 351 RCF participants

- 226(64%) of PWD rated their own QoL using the QoL-AD scale
- higher MMSE (median 17; IQR 12-21) compared with people who were not able to self-rate the QoL-AD (median 5; IQR 0-11; p<0.001)
- staff informant ratings obtained for most PWD (92% using the QoL-AD and 99% using the ADRQL; Table 1)
- Few cases where family ratings were the only informant rating available (8 [2.2%] for the QoL-AD and 2 [0.0%] for the ADRQL
- Most people with dementia can rate their own QoL; subsequent data suggests these ratings are valid

2. Do PWD and their carers agree when rating QoL?



Bland-Altman Plot of Agreement self-report vs proxy's opinion

Self and Informant Ratings of QOL of PWD living in RCF

QOL-AD Rater	n (%) 351	Mean score ± SD	Mean difference (95% CI)$^+$, n pairs with data	Pearson Correlation$^+$
Self rated	226 (64%)	41.5±5.9		
Staff rated	324 (92%)	32.1±7.4	-7.8 (-8.8, -6.7), 208 pairs	0.303 (p<0.001)
NOK rated	292 (83%)	32.4±8.2	-7.2 (-8.5, -6.0), 189 pairs	0.309 (p<0.001)

+Reference is self rated QOL-AD and staff rated ADRQL respectively

Conclusion

- Informant ratings tend to underestimate self-ratings

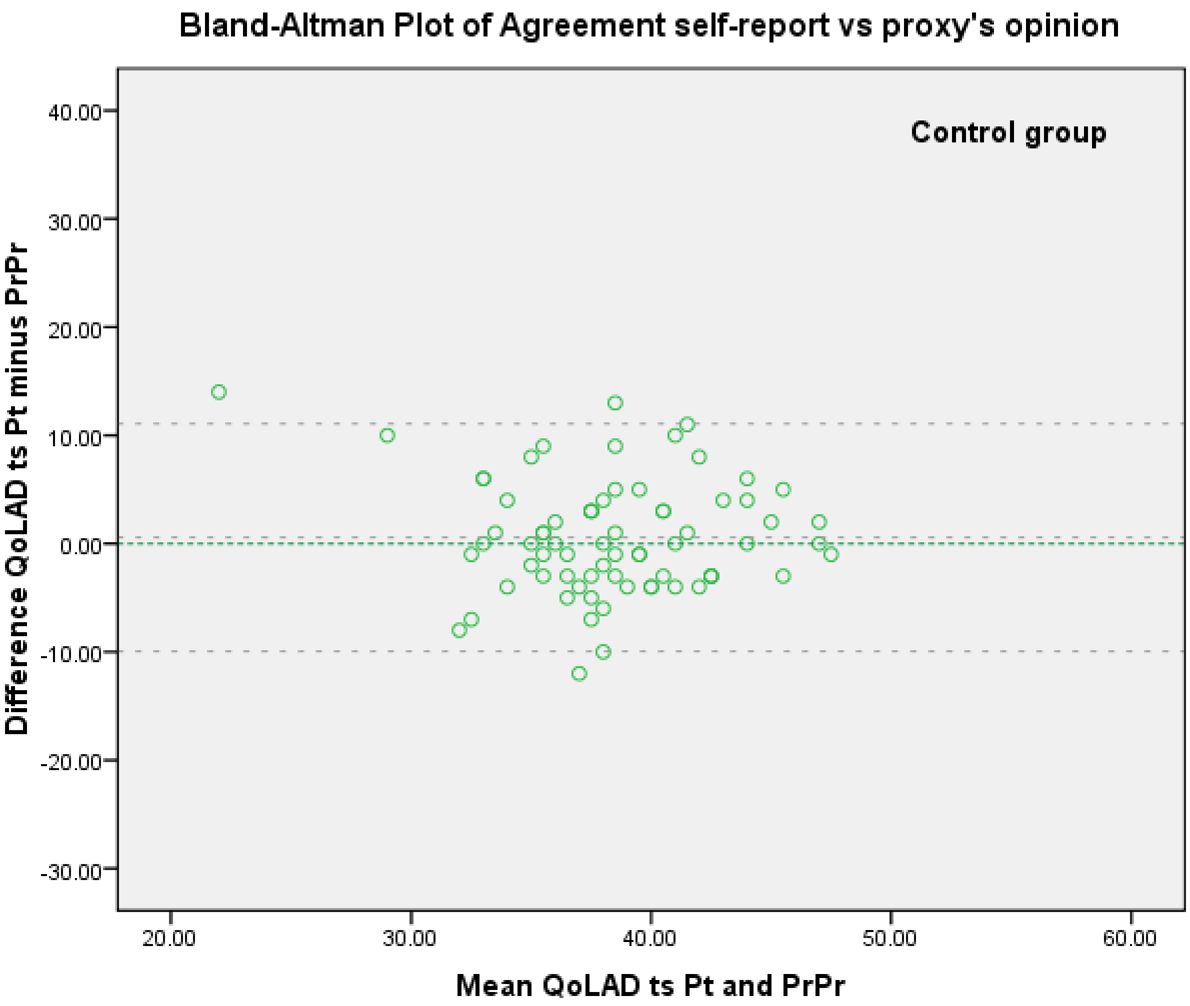
- PWD-C and their carers show acceptable agreement in QoL-ratings

- systematic bias with patients rating their QoL as higher than their carers do

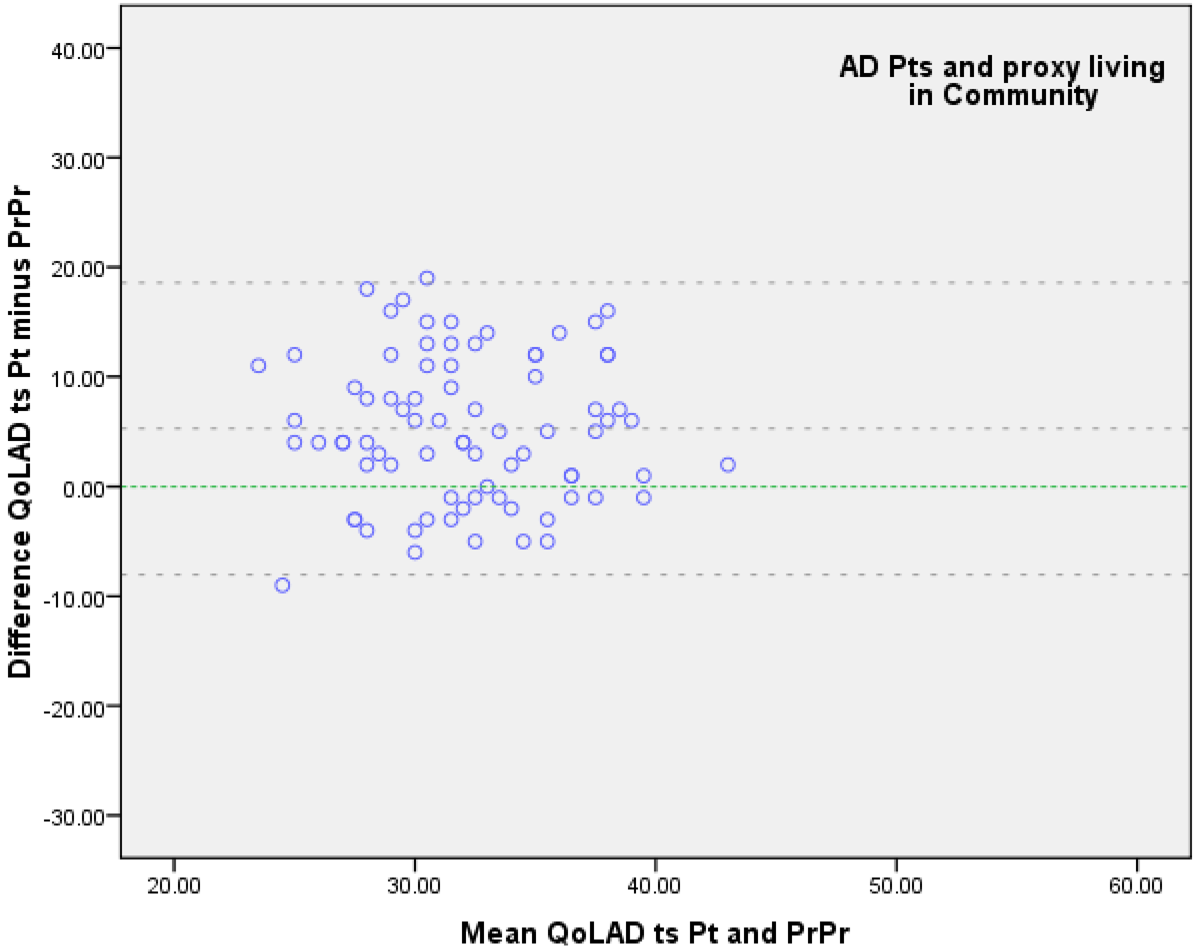
- they seem to “agree to disagree”

- Discrepancies in ratings of QoL should be acknowledged by clinicians and service providers, in order to meet the needs of PWD themselves.

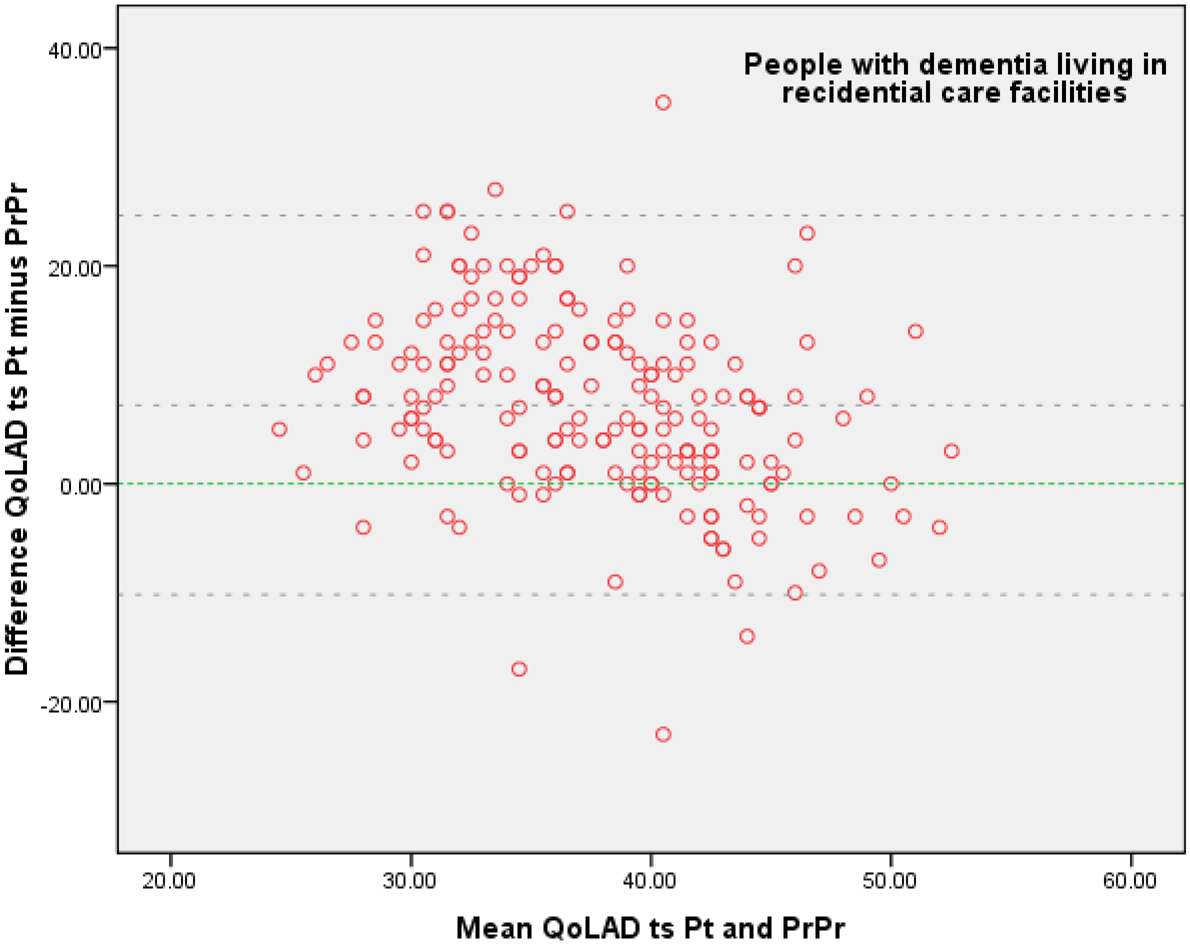
3. Is (dis)agreement the same among different groups of PWD?


Bland-Altman Plot of Agreement self-report vs proxy's opinion
Control group
Difference QoLAD ts Pt minus PrPr
40.00
30.00
20.00
10.00
0.00
-10.00
-20.00
-30.00
20.00
30.00
40.00
50.00
60.00
Mean QoLAD ts Pt and PrPr

Bland-Altman Plot of Agreement self-report vs proxy's opinion



Bland-Altman Plot of Agreement self-report vs proxy's opinion



Conclusion

- There is substantial variation in QoL rating, between different raters, especially for PWD-RCF.

- There seems to be greater difference for individuals with lower ratings of QoL.

4. Does it matter how we ask informants about QoL?

We examined NOK informant report from two perspectives

QOL-AD rated by informants twice:

1. informant-proxy perspective
2. informant-patient perspective

Pt and NoK/informant – e.g. mother and daughter

1. Self-report

2. Informant-patient report

How do you think <u>your mother</u> would rate her QoL?

3. Informant-proxy report

How would <u>you</u> rate your mother's QoL?

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Data on perspectives from QoLCog study

- Mean QoL-AD ts by self-rating (34.7±5.3) higher than proxy-proxy rating (29.5±5.4; t-paired=7.04, p<0.001).
- Mean QoL-AD ts by self-rating also higher than proxy-patient rating (32.1±6.1; t-paired=3.91, p<0.001).
- Proxy-proxy ratings lower than proxy-patient ratings (t-paired=4.60, p<0.001).
- Only 2.5% did not agree with the proxy-proxy ratings (i.e. fell outside the +-1.96SD range), and 5% self-ratings did not agree with the proxy-patient ratings.

5. What factors are associated with patients’ and carers’ QoL-ratings?

Final predictive models of three different views

Predictors	Beta coefficient	R2	Adj R2	p
Self-ratings		.458	.435	<.0001
Anti-Alzheimer drugs	2.10 (2.17) p=.033*			
GRAD	-2.94 (-3.06) p=.003**			
HADS depression squared transformed	-3.43 (-6.01) p<.001***			
Constant	49.23 (15.29) p<.001***			
Proxy-proxy ratings		.447	.396	<.0001
Number of medication	-.32 (-2.23) p=.029*			
CAMCOG-R	.11 (3.10) p=.003**			
HADS anxiety squared transformed	1.49 (2.45) p=.017*			
HADS depression squared transformed	-1.73 (-2.18) p=.033*			
NPI ts squared transformed	-1.01 (-3.23) p=.002**			
Living together (yes 0, no 1)	-3.43 (-2.89) p=.005**			
Constant	28.53 (9.88) p<.001***			
Proxy-patient ratings		.375	.329	<.0001
CAMCOG-R	.13 (3.07) p=.003**			
Carer age	-.08 (-2.02) p=.048*			
HADS depression squared transformed	-2.77 (-3.24) p=.002**			
NPI ts squared transformed	-1.97 (-2.25) p=.027*			
NPI burden of care squared	2.28 (2.07) p=.042*			
Constant	35.38 (8.40) P<.001***			

Absolute value of t-statistics in parentheses. * $P \leq 0.05$;** $P \leq 0.01$; *** $P \leq 0.001$

Factors associated with 5 rating of QoL among 226 PWD-RCF able to self rate

Variable	QOLAD Self	QOLAD Staff	QOLAD NOK
Age >86 years	0.08 (-1.47, 1.63)	-0.59 (-2.58, 1.40)	**2.67 (0.34, 5.01)**
Male Gender	1.17 (-0.59, 2.94)	1.20 (-1.08, 3.48)	2.51 (-0.29, 5.31)
MMSE <10	-1.27 (-3.35, 0.81)	**-3.19 (-5.91, -0.47)**	**-4.47 (-7.74, -1.20)**
GP review	-0.64 (-2.42, 1.15)	-0.52 (-2.85, 1.80)	**-3.04 (-5.73, -0.36)**
CMA	-0.08 (-2.07, 1.90)	1.89 (-0.60, 4.39)	-1.06 (-3.95, 1.83)
Case conference	-1.43 (-3.22, 0.36)	-0.22 (-2.57, 2.13)	-2.09 (-4.84, 0.66)
Pain assessment	-0.60 (-2.27, 1.06)	0.43 (-1.73, 2.58)	1.50 (-1.14, 4.13)
Restraint documented	**-3.94 (-5.99, -1.89)**	-2.48 (-5.19, 0.22)	**-3.38 (-6.66, -0.10)**
Restraint observed	**-4.08 (-7.00, -1.16)**	-3.07 (-6.70, 0.56)	**-6.21 (-10.80, -1.62)**
Perimeter secure	0.04 (-1.79, 1.86)	-0.48 (-2.83, 1.88)	-1.85 (-4.65, 0.94)
Hospital Presentation	-1.06 (-3.96, 1.84)	**-5.75 (-9.47, -2.03)**	-4.80 (-9.63, 0.04)
Falls (last month)	**-2.32 (-4.34, -0.30)**	**-5.15 (-7.61, -2.70)**	**-4.21 (-7.30, -1.11)**
>10 medications	-1.50 (-3.02, 0.03)	-0.65 (-2.62, 1.33)	0.11 (-2.29, 2.50)
Weight >60 kg	0.88 (-0.64, 2.40)	1.34 (-0.60, 3.28)	0.34 (-2.03, 2.71)
Decreasing weight	1.05 (-0.59, 2.69)	1.10 (-1.06, 3.25)	**3.57 (1.01, 6.13)**
Pain (RVBPI)	**-3.46 (-5.34, -1.57)**	0.08 (-2.34, 2.50)	**4.58 (1.69, 7.46)**
Pain (PAIN-AD>1)	**-4.93 (-7.59, -2.26)**	-1.60 (-4.95, 1.76)	0.55 (-3.81, 4.92)
NPI >14	-1.50 (-3.03, 0.03)	**-5.36 (-7.21, -3.52)**	**-3.72 (-6.07, -1.37)**
Staff distress	-1.47 (-3.03, 0.09)	**-3.76 (-5.71, -1.82)**	**-3.00 (-5.39, -0.61)**

mean differences (95%CI) relative to comparison group in unadjusted* quality of life scores associated with predictor variables (e.g., age >86 years compared with age <86 years, male cf female)

Factors associated with difference in QoL self ratings by PWD-RCF

- Restraint
  - documented (mean difference -3.9; 95% CI -6.0, -1.9)
  - observed (mean difference -4.1, 95% CI -7.0, -1.2)
- falls in the last month (mean difference -2.2; 95% CI -4.4, -0.3)
- pain
  - reported (mean difference -3.5; 95%CI -5.3, -1.6)
  - observed pain (mean difference -4.9, 95% CI -7.6, -2.3)

Factors associated with QoL informant rating for PWD-RCF

- Falls in the last month (only factor consistently and significantly associated with informant ratings of QoL as well as self rating)
- severe cognitive impairment
- neuropsychiatric symptoms
- care giver distress
- GP review, case conferencing, documented restraint, a secure perimeter, and hospital presentations also tended to be consistently (but not always significantly) associated with lower informant QoL ratings by family and staff

Regression:

Factors associated with self rated QoL-AD among PWD-RCF

Significant univariate associations with self rated QoL-AD

- restraint (documented and observed)
- number of medications
- falls in the prior month
- pain (reported and observed)
- NPI-NH (both overall score and staff distress score)

Final parsimonious multivariate model (adjusted $R^2 = 0.128$).

- documented restraints (*B*= -0.232)
- reported pain (*B*= -0.251)
- NPI-NH score (*B*= -0.158)

Univariate regression analyses (N=340)

	QoL-AD ts								
	By Pt self-report			By carer as proxy			By carer's opinion		
	β coef.	95%CI	*p*	β coef.	95%CI	*p*	β coef.	95%CI	*p*
Controls (N=72)									
Age	-.10	(-.29, .08)	n.s.	-.08	(-.26, .11)	n.s.	-.02	(-.22, .19)	n.s.
Gender	-1.29	(-3.59, .99)	n.s.	-2.24	(-4.47, -.02)	**.048**	-1.71	(-4.19, .77)	n.s.
MMSE-ts	.95	(.26, 1.64)	**.008**	.09	(-.63, .83)	n.s.	.09	(-.70, .88)	n.s.
MMSE -group	-1.12	(-5.66, 3.43)	n.s.	-.84	(-5.31, -.63)	n.s.	-.93	(5.87, 3.99)	n.s.
NPI-ts	-.22	(-.37, -.07)	**.004**	-.08	(-.23, .08)	n.s.	-.14	(-.31, .02)	n.s.
NPI -cgd	-.48	(-.77, -.19)	**.001**	-.25	(-.55, .05)	n.s.	-.30	(-.63, .03)	n.s.
PWD-C (N=79)									
Age	-.00	(-.49, -.03)	**.026**	-.06	(-.23, .12)	n.s.	.02	(-.14, .17)	n.s.
Sex Pt	-1.89	(-4.42, .64)	n.s.	-.50	(-3.47, 2.46)	n.s.	-.68	(-3.28, 1.91)	n.s.
MMSE-ts	-.26	(-.49, -.03)	**.026**	.23	(-.04, .51)	n.s.	.34	(.11, .57)	**.004**
MMSE-group	1.69	(.06, 3.32)	**.043**	-.83	(-2.76, 1.09)	n.s.	-1.77	(-3.42, -.12)	**.036**
NPI -ts	-.08	(-.17, .02)	n.s.	-.15	(-.26, -.05)	**.005**	-1.17	(-.26, -.09)	**.000**
NPI -cgd	-.13	(-.29, .04)	n.s.	-.17	(-.36, .02)	n.s.	-.20	(-.37, -.04)	**.017**
PWD-RCF (N=189)									
Age	.06	(-.05, .18)	n.s.	.04	(-.14, .21)	n.s.	.15	(-.01, .31)	n.s.
Sex Pt	-1.24	(-3.29, .82)	n.s.	-2.55	(-5.76, .65)	n.s.	-2.67	(-5.57, .22)	n.s.
MMSE-ts	.03	(-.12, .18)	n.s.	**.33**	(.11, .55)	**.003**	.32	(.12, .53)	**.002**
MMSE -group	-.01	(-1.27, 1.26)	n.s.	-2.08	(-3.98, -.18)	**.032**	-2.24	(-3.99, -.47)	**.013**
NPI -ts	-.04	(-.07, -.00)	**.028**	-.05	(-.10, .00)	n.s.	-.05	(-.09, -.00)	**.050**
NPI -cgd	-.06	(-.15, .03)	n.s.	-.09	(-.22, .05)	n.s.	-.07	(-.20, .06)	n.s.

Conclusion/implications

Informant ratings of QoL of people with dementia appear to be associated with factors which are not associated with self ratings.

when developing interventions aimed at improving patients' QoL our results suggest that in patients' view we should focus on decreasing feelings of depression, using anti-Alzheimer's drugs and taking their level of insight into account.

On the other hand, in carers' view we should focus on cognition and psychopathology (in particular depression and anxiety).

Moreover, proxy-proxy ratings were significantly lower than proxy-patient ratings and the burden of care was not an explanatory factor for the proxy-proxy ratings.

- Tendency for factors such as case conferencing and GP review to be associated with lower informant QoL ratings
  - Unexpected
  - possibly error due to chance
  - confounding due to active clinical problems
  - recognition of unmet needs

6. Does cognitive impairment influence QoL ratings?

Variation in QoL related to MMSE

- Variance (R^2) of self-reported QoL explained by the MMSE total score
  - Controls 9.7%
  - PWD-C 6.3%
  - PWD-RCF 0.1%

- variance (R^2) of Informant-as-proxy reported QoL explained by the MMSE
  - Controls 0.1%
  - PWD-C 3.7%
  - PWD-RCF 4.7%

- variance (R^2) of Informant-opinion reported QoL explained by the MMSE
  - Controls 0.1%
  - PWD-C 10.1%
  - PWD-RCF 4.9%

Importance of MMSE

- Significant linear association between difference in QoL-ratings and MMSE score
- linear trend -0.43, p=<.001
- This trend not confounded by age, gender or NPI
- Cognitive impairment (as measured with the MMSE) associated with the perception of QoL by patients and carers differently.

7. Do these data have practical implications?

QoL ratings by different raters with different perspectives are associated with different predictors

QoL ratings are not interchangeable

Choice of viewpoint may have considerable impact

Relevant to clinical decisions aimed at improving QoL in AD.

Practical Implications

- Be mindful of who you ask!

- Consider disparate views from people themselves and informants

- Consider determinants from the person’s point of view

Conclusions

(1) Overview of our studies: how can we measure QoL in dementia?

- asking people themselves is the ideal

(2) Do PWD and their carers agree when rating QoL?

- Agree to disagree!

(3) Is (dis)agreement the same among different groups of PWD?

- No, factors such as place of residence seem important

(4) Does it matter how we ask informants about QoL?

- Yes, explaining the proxy role appears to be helpful

(5) What factors are associated with patients' and carers' QoL-ratings?

- Several factors appear important

(6) Does cognitive impairment influence QoL ratings?

- Varies according to rater and degree of cognitive impairment

(7) Do these data have practical implications?

- Yes, given the importance of understanding QoL of PWD

Fundamentally, the privileged access to ones own mind, and the way we subjectively weigh all the relevant domains of our QoL, means that nobody knows better.

Even if the proxy is a knowledgeable informant and is concerned with the well-being of their older adult with dementia, the proxy is also someone that can be imposed by their own subjectivity upon their judgement, which is likely to be affected by their own sense of well-being.

(Thorgrimsen et al., 2003)

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QolCog Study
WACHA
UWA Perth

DIRECT
Dementia in Residential Care: Education Intervention Trial

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