Clinical and economic predictors of quality of life in dementia

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1. Background

- To date, multivariate analyses of quality of life (QoL) in dementia are relatively rare (Banerjee et.al_2009). This study aimed to measure QoL of persons with dementia and their family-caregivers.
- The study also examined what interventions from primary and secondary care in New Zealand are helpful for enhancing QoL and what these interventions cost.

2. Methodology

Inclusion criteria

Patients

- Alzheimer's dementia, vascular dementia or mixed dementia, any stage
- Diagnosed recently, within 3 months prior to baseline interview
- Living in community
- Having primary informal family-caregiver

Caregivers

- Being patient's primary informal family-caregiver (family member or friend)

Baseline interviews ($^{1}/_{12}$): Completed

Patients

- Stage of illness: Clinical Dementia Rating (CDR) Scale
- Cognition: Modified Mini Mental State (3MS) Examination
- QoL: Quality of Life-Alzheimer's Disease (QOL-AD) Scale (patient rated) and QOL-ADproxy (caregiver rated)
- Depression: Cornell Scale for Depression in Dementia (CSDD)
- Difficult behaviours: Neuropsychiatric Inventory (NPI)
- Daily functioning: Bristol Activities of Daily Living Scale (BADLS)

Caregivers

- QoL: QOL-AD (QoL)
- Distress: NPI-Distress (NPI-D)
- Perceived burden: Zarit Burden Interview (BI)
- Depression: Geriatric Depression Scale (GDS)
- Subjective level of support from family and friends: Multidimensional Scale of Perceived Social Support (MSPSS)

Secondary measurements

- Direct and indirect costs: Service-Use-Costs-Questionnaire (adaptation of CAS, CATS and RUD)
- Level of satisfaction with formal and informal support: qualitative interview

Service Use and Costs Diaries (12 x $^{4}/_{52}$): Ongoing

Interview at 12-months follow-up ($^{12}/_{12}$): Ongoing

- Repeated baseline measurements
- Caregivers' economic burden: Cost of Care Index (CCI), part 5
- Caregivers' work status: Resource Utilization in Dementia (RUD) Questionnaire

- Note: All correlations are positive unless stated otherwise.

3. Clinical outcomes

- At baseline, patients' difficult behaviours (NPI) and functioning were significantly negatively correlated with patients' QoL. Caregivers' QoL and burden were also correlated with patients' QoL ***(Figure 1)***.
- A later stage of illness predicted more impairment of patients' QoL and of their daily functioning.
- Depressive symptoms in patients negatively impacted their QoL and caregivers' subjective level of burden.
- NPI symptoms were related with depression in patients and with higher level of burden in caregivers.
- Cognition was not a predictor of QoL but it did decrease with illness progression.
- Caregivers' ratings of patients' QoL were significantly negatively associated with the presence of NPI symptoms, patients' daily functioning, and caregivers' distress amongst others.

4. Informal care and support

- At baseline, even though the hours of informal care increased with illness progression and informal care time was correlated with patients' QoL there was no correlation between informal care and caregivers' QoL.
- Formal care (t, n) was unrelated to participants' QoL ***(Figure 2)***.
- Increased informal care was related to burden and depression in caregivers.
- Depression and difficult behaviours in patients increased the need for informal care ***(Figure 3)***.
- Perceived social support (from friends and significant others, less from family) correlated with caregivers own QoL and their proxy ratings of patients' QoL.

Figure 1

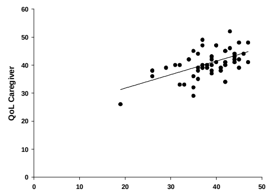


Figure 2

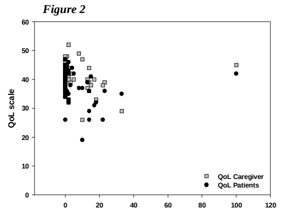


Figure 3

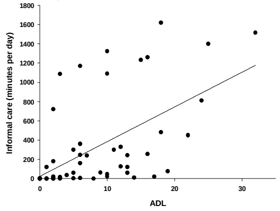
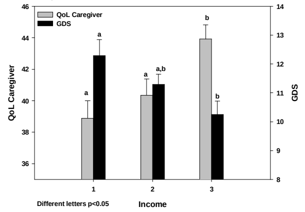


Figure 4



5. Economic burden

- At baseline, lower income impacted negatively caregivers' QoL and increased carers' risk for depression ***(Figure 4)***.
- The subjective financial situation as perceived by patients and caregivers (QOL-AD q12) was correlated with caregivers' burden.
- The financial burden of care (BI q15) was associated with caregivers' and patients' QoL and increased depression and distress scores in carers.
- A higher level of subjective burden in caregivers was linked to less subjective financial security (GDS q23).

6. Conclusions

- Depression in patients and caregivers, each other's QoL, patients' neuropsychological behaviours and functioning, as well as caregivers' burden, and the level of informal care can predict QoL in dementia.
- Reducing the intensity of informal care - by treating depression and difficult behaviours in patients - might reduce caregivers' symptoms of depression and burden with potential to delay institutionalization and reduce costs.
- Developing (financial) incentives that reward informal caregivers for their time spent caring could be a key factor in supporting carers in their role. This might delay the need for permanent professional care and therefore decrease the societal financial burden.

Literature cited

- Banerjee, S., Samsi, K., Petrie, C. D., Alvir, J., Treglia, M., Schwam, E. M., et al. (2009). What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. International Journal of Geriatric Psychiatry, (1), 15-24.

For further information

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