Clinical and economic predictors of quality of life in dementia

Franziska Gallrach¹, Ray Kirkk, Andrew Hornblow¹, Matthew Croucher²
Health Sciences Centre, University of Canterbury, Christchurch, New Zealand¹
School of Medicine, University of Otago, Christchurch²

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 (T₁): 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: Geriatric Depression Scale (GDS)
- 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)
- Subjective level of support from family and friends: Multidimensional Scale of Perceived Social Support (MPSS)

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 T₂): Ongoing

Interview at 12-months follow-up (T₃): Ongoing

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

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.

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.
- 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.

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


For further information

- Please contact: Franziska Gallrach, MA, Ph.D.-Candidate (Health Sciences)
- Email: franziska.gallrach@canterbury.ac.nz or visit our web site at http://www.hsci.canterbury.ac.nz

Note: All correlations are positive unless stated otherwise.