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Actifcare

RELATIONSHIP QUALITY PERCEPTION OF SPOUSES AND ADULT CHILD CARERS OF PEOPLE WITH DEMENTIA

MARIA J. MARQUES¹, BOB WOODS², M. GONÇALVES-
PEREIRA¹ AND THE ACTIFCARE WORKGROUP

¹ CEDOC, NMS/FACULDADE DE CIÊNCIAS MÉDICAS, UNIVERSIDADE NOVA DE
LISBOA, LISBON, PORTUGAL

² BANGOR UNIVERSITY, WALES, UNITED KINGDOM

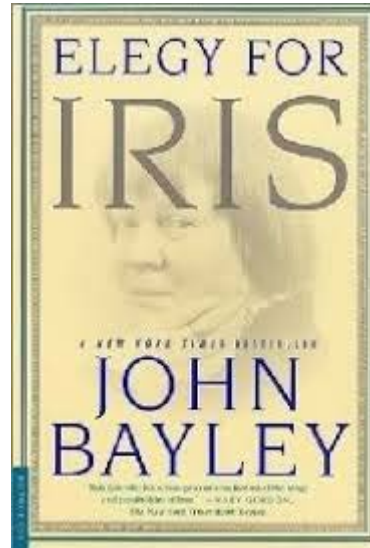
Access to timely formal care

Introduction



Iris Murdoch and John Bailey

Introduction



Elegy for Iris (1999)

The terror of being alone, of being cut off for even a few seconds from the familiar object, is a feature of Alzheimer's. If Iris could climb inside my skin now, or enter me as if I had a pouch like a kangaroo, she would do so.



Why are relationships important in dementia care?

- A good past and present relationship quality in dementia is associated with:
 - ➔ higher quality of life, lower depression and anxiety in both dyad members (Clare et al., 2012; Fauth et al., 2012; Spector et al., 2015)
 - ➔ lower caregiver burden (Clare et al., 2012; Steadman et al., 2007; Springate et al., 2014)
 - ➔ less behavioural disturbances of the person with dementia (Spector et al., 2015)

Introduction



However little is known about the factors that...

- influence relationship quality
- explain possible discrepancies between the perspectives of people with dementia and their caregivers
- explain possible discrepancies among subgroups of caregivers

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Living with dementia: A systematic review of the influence of relationship factors

Astri Ablitt^{a, b}, Gregory V. Jones^c & Jane Muers^c

^a Department of Psychology, University of Warwick, Coventry, CV4 7AL, UK

^b Department of Clinical Psychology, James Starley Building, Coventry, CV1 5FB

^c Coventry and Warwickshire NHS Partnership Trust, Orcha Street, Coventry, CV1 3SR, UK

Published online: 22 Jul 2009.

The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review

Catherine Quinn^a, Linda Clare^a & Bob Woods^a

^a School of Psychology, Bangor University, Gwynedd, Llandudno, LL57 2ZG, UK

Published online: 03 Apr 2009.

Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood

Olivia Wadham^a, Jane Simpson^a, Jonathan Rust^b & Craig Murray^a

^a Division of Health Research, Lancaster University, Lancaster, England

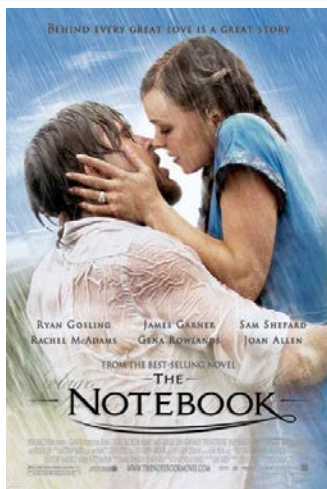
^b Lancashire Care NHS Foundation Trust, Preston, Lancashire, UK
Published online: 26 Mar 2010

Melanie Braun ✉, Urte Scholz, Barbara Bailey, Sonja Perren, Rainer Hornung & Mike Martin

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Introduction



- ➔ Varies along the journey
- ➔ Different for different people
- ➔ Different for different relationship type [spouses/partners; adult child caregivers; other informal caregivers]

Aim

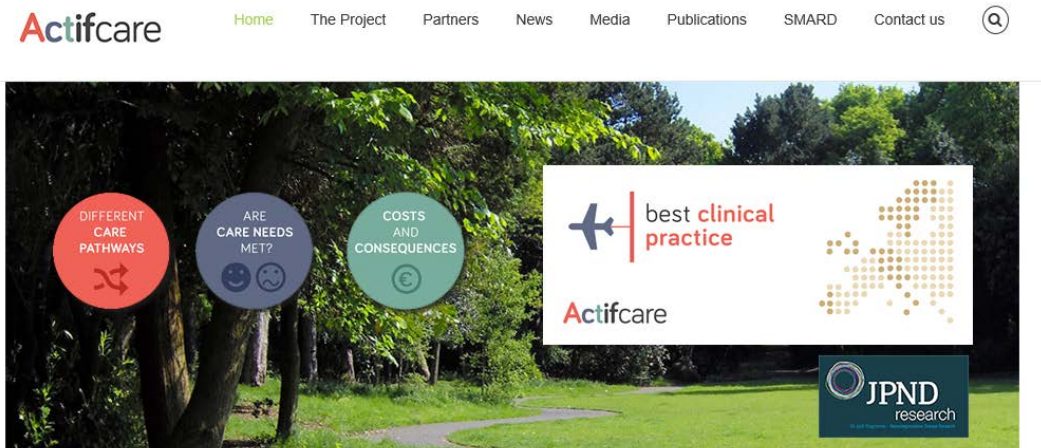


- to examine discrepancies between person with dementia and caregiver perceptions of relationship quality
- to explore factors associated with the relationship quality
- **to examine differences between caregivers' subgroups (spouses and adult child caregivers)**

Context



- Actifcare (Access to Timely Formal Care) EU-JPND project – www.actifcare.eu
- one year cohort study in 8 European countries
- 902 participants; 451 dyads of people with dementia/family caregivers





STEP 01

BASELINE ASSESSMENT BETWEEN NOVEMBER 2014 AND JULY 2015

- The Positive Affect Index (Bengston & Schrader, 1982)
- Closeness, communication, similar views, shared activities, and overall RQ

STEP 02

CROSS-SECTIONAL DATA ANALYZED FOR 451 PEOPLE WITH DEMENTIA AND CAREGIVERS

- 64% spouse/partners; 30% adult-child; 6% other

STEP 03

FOCUS GROUPS, IN-DEPTH INDIVIDUAL INTERVIEWS, BRIEF PHONE INTERVIEWS

- People with dementia: 39
- Informal carers: 56

Results



- Relationship Quality (RQ) rated ↑ by the person with dementia than by caregivers ($t_{431} = 7.547, p = .001$)

RQ rating by caregiver

Higher caregiver's **stress**, **depression** and **neuropsychiatric symptoms** of the person with dementia were related to lower RQ

The **spouse/partner relationship** type and the caregiver's stronger **sense of coherence** were related to higher caregiver's RQ rating

RQ rating by person with dementia

Higher caregiver's **stress** predicted lower RQ

The **spouse/partner relationship** type and higher **caregiver's education** emerged as significant predictors of higher RQ ratings

Results



- No significant differences in the perception of RQ between the two groups overall, although there were differences at an item-level (e.g. **adult children scored lower on shared activities and similarity of views**)
- For **adult child caregivers** RQ was explained mostly by caregiver characteristics (e.g. age; stress)
- For **spouses**, both caregiver and person with dementia variables (e.g. neuropsychiatric symptoms) predicted relationship RQ
- The qualitative data showed differences linked to pre-caregiving quality of relationship, social support and access to/ use of formal care services between caregiver subgroups
- Spouses were most reluctant to access/use formal services, such as home care or day centre, especially if they were women

Discussion / conclusions



- Many people with dementia are able to reliably and accurately rate the quality of the current relationship
- Whilst spouses/partners and adult children may report similar levels of relationship quality, the factors contributing to this perception appear different
- Understanding relationship quality will assist in identifying how best to maintain quality of care and support caregivers who wish to maintain care at home

Next steps



- Longitudinal analysis to explore the factors associated to RQ as well as discrepancies between perspectives
- Interviewing secondary informal caregivers



Iris Murdoch and John Bailey

It is wonderfully peaceful to sit in bed with Iris sleeping and gently snoring. Half asleep again myself, I have a feeling of floating down the river, and watching all the rubbish from the house and from our lives – the good as well as the bad – sinking slowly down through the dark water until it is lost in the depths. Iris is floating or swimming quietly beside me (...) ([Elegy for Iris, 1999](#))

Memory may have faded, but something of the past is known; identity remains intact, because **others hold it in place**; thoughts may have disappeared, but there are still **interpersonal processes**; feelings are expressed and meet a validating response (...) (Kitwood, 1997 pp. 69)



Maria J. Marques

maria.marques@nms.unl.pt

CEDOC, NMS/Faculdade de Ciências Médicas,
Universidade Nova de Lisboa, Lisbon, Portugal