‘It’s good to talk to someone about these issues’

Facilitating shared decision making with people with MCI/early stage dementia and their family caregivers

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Overview

• Study
  – Location/Participants
  – Intervention Model

• Case studies
  – Dyads

• Value of early intervention
  – Challenges
  – Benefits
Study Objectives

1. Establish the effectiveness of working with people with MCI/early stage dementia and their family caregivers (the Dyad) and;
2. Recruit and train an existing practitioner workforce from within community aged care services to deliver the intervention.
Study Locations

- BRISBANE NORTH
- SUNSHINE COAST
- BRISBANE SOUTH
- GOLD COAST

Control: Red
Intervention: Green

SE Queensland
Inclusion Criteria

Dyads

• Individuals aged 65 or over with symptoms consistent with and/or a diagnosis of early stage dementia (CDR 0.5 - 1.0) living in the community
• Primary family caregivers living with or providing regular support to the above.

88 Dyads Recruited
45 – Intervention Group
43 – Control Group
Inclusion criteria

Intervention Staff

- Registered Nurses with more than one year’s community nursing experience and experience in supporting PWD and their family caregivers.
- Personal Care Workers with Certificate III in Aged Care, more than one year’s community support service experience and experience in supporting PWD and their family caregivers.
- 23 Community Practitioners Recruited
  3 - Registered Nurses
  20 – Personal Care Workers
Intervention Model

Intervention

- Early Diagnosis Dyadic Intervention (EDDI) (Whitlatch et al.; 2006)

Structure

- Delivered in the home by a trained facilitator
- Seven sessions lasting 60-90 minutes
- Intervention sessions designed as planning meetings

Goals

- Encourage the person with dementia to talk through their preferences for care at a time when they can still do so
- Reduce the risk of dyadic relationship stress, and potential for breakdown of the care giving relationship, by encouraging the dyad to expand their caring network beyond the primary family caregiver
Sessions

During intervention sessions staff;

• Provided information and advice
• Initiated a pathway into support networks
• Facilitated the active participation of the person with dementia (PWD) in the information sharing, decision making and planning process.
Case Study Dyads

Dyad A
- Mother & Daughter
- CG non-resident

Dyad B
- Husband and Wife
- CR Husband
- Lived in a Retirement Village

Dyad C
- Neighbors/Friends
- CG non-resident
- CR lived alone in own house
Dyad A

Issues
• CR apparent reluctance to accept diagnosis
• CG very anxious over CR ability to live independently and her future care setting

Outcomes
• CR & CG accepted cognitive changes
• CR approved for higher level community care
• CG accepted CR preference for RAC when no longer able to live independently
Dyad B

Issues

• CG experiencing difficulty in finding appropriate community support
• CR reserved and anxious

Outcomes

• CR ‘wasn't good with words’ but engaged in individual care related discussions
• CG reluctant to acknowledge available support networks or listen to CR preferences
Dyad C

Issues

• CR driving capacity
• CR determination to remain at home
• CG decision making status as not related to CR

Outcomes

• Alternative transport options arranged and CR relinquished driving
• Granny flat created for live-in carer
• CG acted as informant for CR nieces
Early Intervention

The value for the dyad;

• Learn strategies to manage the changes which will occur
• Increase awareness of community support services and how to access them
• Provides and opportunity for the PWD to take an active role in planning for the future
• Assists caregivers’ to make personal and difficult decisions with greater confidence
Early Intervention

The value for community service staff

• Early exposure to people with dementia and their caregivers before they reach a crisis point

• Increased understanding of how expectations and values are expressed and negotiated in the early stages

• Enhanced job satisfaction through increased knowledge & scope of practice
Challenges

• Intervening at an appropriate level whilst maintaining program integrity
• Preparing for a future in which needs will increase is confronting/depressing
• Sometimes the PWD never had a voice within the relationship!
• Acknowledging the complex dynamics of parent/adult child relationship or the limited influence a friend may have over family members
Feedback

• ‘I have been more proactive in communicating [husband’s] needs with his sons, have employed someone to clean the house and am involving friends more in [his] care’ [CG].
• ‘We would not be as well informed or as confident about making choices for the future’ [CG].
• ‘Very helpful, they help you feel more confident by knowing there is help available’ [PWD]
• ‘Strengthened my relationship with [CG]’ [PWD]
• ‘Different from routine practice – an opportunity to stretch myself’ [IF]
Conclusion

• Forward planning and early introduction to community service providers are critical elements in empowering dementia dyads and fostering appropriate identification of and access to support along the disease continuum.

• The personal characteristics, practical knowledge and experience of the individuals chosen to act as facilitators were favourable to the dyads so their involvement yielded maximum benefits.
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Participants

• PWD & FCG dyads
• Intervention Facilitators, Intervention Trainers, Graphic Designers
Thank you

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