Alignment Between Informal Carers and Formal Dementia Care Workers: Perspectives on Community Service Delivery

Dr Kate-Ellen J. Elliott¹ ² *, Dr Christine M. Stirling², Prof Andrew L. Robinson² and A/Prof Jennifer L. Scott¹ ².

¹ School of Psychology, Faculty of Health Science, University of Tasmania, Private Bag 30, Hobart, Tasmania, Australia, 7001.
² Wicking Dementia Research and Education Centre, Faculty of Health Science, University of Tasmania, Private Bag 143, Hobart, Tasmania, Australia, 7001.
Dementia is a public health priority

• In 2010, 35.6 million people had dementia worldwide
  • One new case every four seconds & will treble by 2050

• In 2011, 298,000 Australians had dementia
  • 62% were women, 74% were aged 75 and over, 70% lived in the community
  • aged 65 +, almost 1 in 10 (9%) had dementia, aged 85 +, 3 in 10 (30%) had dementia.
  • 23,900 Australians under the age of 65 with dementia in 2011

Carers of people with dementia

- Most care for people with dementia is provided by family members or informal support systems in the community.

- In Australia, estimates show that it would cost more than $30.5 billion per year to replace all informal dementia carers.

- Enormous public health value of informal care can come at great cost to the carer (e.g., poor mental health).

- Projected shortage of more than 153,000 paid and unpaid carers for people with dementia by 2029.

(Access Economics, 2005; 2009; Cuijpers, 2005; Wimo & Prince, 2010; Zarit & Femia, 2008)
Carers of people with dementia

• Important source of the evaluation of the health and aged care system

• Valuable resource for ideas and suggestions on future care packages and services

• Most research is focused on residential not community care service delivery
  • Even less on whether informal carers and paid formal carers perspectives align

(Lee et al., 2009; Litherland, 2008)
Aim

• to assess the alignment of care expectations for informal and formal carers of people with dementia living in the community
Methods

• Qualitative data was collected and analysed independently for community-based;

• Informal dementia carers
  • Workshop

• Formal dementia care workers
  • Semi-structured interviews

• Data transcribed and coded for themes
  • Very good inter-coder reliability
Brief demographics compared

N= 61 (36 Informal carers; 25 formal care workers)

<table>
<thead>
<tr>
<th></th>
<th>Informal dementia carers</th>
<th>Formal dementia care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>N = 27 (75%)</td>
<td>N = 22 (88%)</td>
</tr>
<tr>
<td>Male</td>
<td>N = 8 (22%)</td>
<td>N = 3 (13%)</td>
</tr>
<tr>
<td>Over 50 years</td>
<td>N = 32 (88%)</td>
<td>N = 14 (38%)</td>
</tr>
<tr>
<td>Years in the role</td>
<td>7 yeas on average (SD = 7.8)</td>
<td>6 years on average (SD = 4.3)</td>
</tr>
</tbody>
</table>
Similar practical caring roles & unmet needs

• More information about dementia
  • ↑ in community awareness make roles easier

• Isolated
  • Informal carers felt “tied to the house”
  • Formal carers felt “working alone is a downside”

• Wanted more time to spend caring
  • Not just on practical tasks
  • Also to promote social support and interaction
Coping with care roles

• Informal carers
  • Counselling and psychological assessment and treatment

• Formal care workers
  • Need for reflective work practices (e.g., regular meetings with co-workers to discuss clients care needs and “debrief”)

• Both carer types
  • Want better access to financial assistance and resources (e.g., electronic lift chairs)
Positive care relationship

• Informal carers on workers
  • “appreciative of workers”
  • “need acknowledgement of their good work”
  • “use kind speech”
  • “listen and act”

• Formal care workers on people with dementia and their carers
  • Personal need for interaction with others
  • Important skills included “listening”, “being respectful and empathic”

• Both carer types
  • Views on each other were generally positive, minority some concerns
  • Good relationship meant good care
Challenges for the care relationship

• Informal carers
  • “workers are good once they are established”
  • “workers need to care more”
  • “lack understanding about disability”

• Formal care workers
  • “conflict with carers and family members”
  • “unrealistic demands” of clients and
  • “unsupportive and critical families”

• Both carer types
  • Starting a relationship with a person with dementia
Workforce

- Informal carers
  - staff shortages can influence the continuity of care for the person with dementia
  - low numbers of specialised health professionals in their area,
  - workers need training and knowledge of dementia

- Formal carer workers
  - more specialised training
  - higher levels of qualifications to be held by workers in dementia care in the future.
  - changes in the clients they care for can be difficult to manage, particularly in light of the loss of relationship and trust that was established over time
  - recognised that worker knowledge of dementia helps the caring role

- Both carer types
  - Worker continuity a concern
Community-based services

• Informal carers
  • operate under a “case management approach”,
  • as “enhanced communication within services”, and
  • “more flexibility” for individuals needs were required
  • “companionship” for care recipients a need

• Formal carer workers
  • more services were needed to focus on the social participation of people with dementia
  • importance of making time to “have a cup of tea” to provide social interaction

• Both carer types
  • Community excursions and more social activities designed for people with dementia were desired by carers.
  • improvements in funding would assist problems of access to resources for people with dementia and their carers
Quotes

“I would like to have more support ‘cos I am tied to the house. The two support workers are pleasant and helpful, but we want more skills and qualified workers”

A comment made by a female informal carer.

“There will be more clients and I think probably there has to be more information for us on how to handle the situation and more education for us. Like training, for example”

A comment made by a female formal care worker.
Strong alignment between carers

• more information about the services available
• better community understanding about dementia needed
• specialised training for workers was commonly reported
• a desire to improve the consistency of care
• more flexible services

• Limitations – data collected using different methods
Conclusion

• Carers want improvements in access to
  • information and support,
  • workforce training and
  • service delivery in the community setting.

• A broad approach should be applied to capacity building for community-based dementia care.
  • May include strategies that improve community dementia awareness, workforce skills and organisational systems to reform future services.
References


Dr K Elliott © 2013