Developing a medication management information guide for ethnic minority family caregivers of people living with dementia

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Developing a medication management information guide for ethnic minority family caregivers of people living with dementia

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Background

• Current projections suggest that the 298,000 Australians living with dementia in 2011 will increase to 400,000 by 2020 (AIHW 2012a).

• In Australia, more than 70% of older adults living with dementia reside in a community setting (AIHW 2012a).

• A 2009 national survey identified that 33% of community-dwelling people living with dementia (ABS 2010; AIHW 2012a) were from ethnic minority backgrounds.
• Family caregivers spend **more than 40 hours per week** providing many different care roles (AIHW 2012a) for these community-dwelling people living with dementia.

• **Medication management** is an **important part of the family caregiver’s role**, helping to improve health outcomes and reduce hospitalisations (Arlt et al. 2008).

• Medication management **responsibilities increase**, as their **care recipient’s cognitive abilities deteriorate** (Cotrell et al. 2006, Kaasalainen et al. 2011), from a baseline of approximately **54% to over 90%** in the later stages of dementia (Thorpe et al. 2012).
• From a family caregiver’s perspective, medication management includes (Smith et al 2003)
  – maintaining continuous supplies of medications
  – assisting with administration
  – making clinical judgements
  – communicating with health care providers and care recipients
• Effective and safe medication management involves (Brodaty and Green 2002)
  – being informed about what is prescribed
  – asking relevant questions of health care professionals
  – monitoring for medication adherence
  – watching for medication-related side effects
  – granting or refusing consent for medications where the care recipient is no longer able provide consent
• Despite these complexities, medication management for informal caregivers remains an under researched topic area.

• Few studies have focused exclusively on family caregivers of people living with dementia (Cotrell et al. 2006, Kaasalainen et al. 2011, While et al. 2012).

• Even fewer studies have focused on the experience of ethnic minority family caregivers (CIRCA 2008)
Research Aim

• To explore the views of ethnic minority family caregivers of people living with dementia and their medication management experience
Research design

• University of Wollongong Human Research Ethics Committee Approval

• **3 Focus groups** and **7 individual interviews** using semi structured interview guide.

• Family caregiver participants: Italian, Greek, Macedonian, Portuguese, Croatian and Dutch

• Data was transcribed from audio recordings

• Qualitative data collected was thematically analysed (3 independent reviewers)
### Demographic information of the 22 focus group participants

<table>
<thead>
<tr>
<th>Nationality</th>
<th>Number of caregivers</th>
<th>Gender</th>
<th>Carer status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Italian</td>
<td>6</td>
<td>all female</td>
<td>spouse caregivers</td>
</tr>
<tr>
<td>Macedonian</td>
<td>11</td>
<td>8 female/3male</td>
<td>spouse caregivers</td>
</tr>
<tr>
<td>Portuguese</td>
<td>5</td>
<td>all female</td>
<td>4 spouse caregivers/ 1 adult child caregiver</td>
</tr>
</tbody>
</table>
# Demographic information of the 7 one-on-one interview participants

<table>
<thead>
<tr>
<th>Nationality</th>
<th>Number of caregivers</th>
<th>Gender</th>
<th>Carer status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Italian</td>
<td>2</td>
<td>female</td>
<td>adult child caregivers</td>
</tr>
<tr>
<td>Greek</td>
<td>2</td>
<td>female</td>
<td>1 adult child/1 spouse caregiver</td>
</tr>
<tr>
<td>Dutch</td>
<td>1</td>
<td>female</td>
<td>spouse caregiver</td>
</tr>
<tr>
<td>Croatian</td>
<td>1</td>
<td>female</td>
<td>adult child caregiver</td>
</tr>
<tr>
<td>Macedonian</td>
<td>1</td>
<td>female</td>
<td>adult child caregiver</td>
</tr>
</tbody>
</table>
Four Major Themes

1. Medication management is a source of stress for family caregivers
2. Medication management may be a point of conflict that needs to be carefully controlled
3. Family support of this caregiving role is considered to be extremely important
4. Family caregivers believe that they would benefit from sources of external information and support regarding medication management
1. Medication management is a source of stress for family caregivers

• ‘My husband ... he takes his own medication... but he only takes the blood pressure tablets because the other tablets he thinks do not do anything ... So I got a big problem.’ (Italian focus group)

• ‘We were finding too much on the floor, not only from hers but also from his....He took her medication instead of his. Oh it was just horrendous, it was just horrendous!’ (Greek adult child caregiver)
• ‘So we started hiding the medication in food, we crushed it... put it in some yoghurt....some of them weren’t crushable so we put them whole into liquorice or something that has a strong taste over powering the other one.’ (Italian adult child caregiver 1)

• ‘There’s so many... he was so confused, there were so many medications at the table and different times of the day.’ (Greek adult child caregiver)

• ‘...he was put on.... I don’t know what they are for or what they are.’ (Macedonian focus group)
2. Medication management may be a point of conflict that needs to be carefully controlled

• ‘When we got the blister packs he was so angry with us he said “what do you think!? Do you think I can’t manage my medications!?”’ (Greek adult child caregiver)

• ‘It’s very frustrating …making sure that she’s got all her medications….One time I did frankly tell her what she had (dementia) and she basically told me off and she told me “One should never say that especially to her own mother!”’ (Croatian adult child caregiver)
2. Medication management may be a point of conflict that needs to be carefully controlled

• ‘So we decided to take the blister packs away from him.... then my father-in-law would get really agitated and say you know “you’re taking away my responsibility.”

And so in the end ... we took them back. We just couldn’t handle it anymore and we let him do it.’

(Greek adult child caregiver)
3. Family support of this caregiving role is considered to be extremely important

• ‘Usually one of us will try and get her to the doctors and one of us will take her to the chemist to pick up her scripts.’ (Italian adult child caregiver 2)
4. Family caregivers believe that they would benefit from sources of external information and support regarding medication management

• ‘But he said ‘Doctors given me one a little bit different’....I don’t know why, maybe he has given him something a little bit stronger. ‘(Dutch spouse caregiver)

• ‘The one that we had in ‘D’ that man (pharmacist) knew...because we had been going there for so many years .....those people up there (new pharmacy staff)...I don’t even know who is the owner or who is the pharmacist.’ (Dutch spouse caregiver)
Conclusion

• Medication management can be problematic, especially during the transition phase of the care recipient’s cognitive decline

• One of the best ways to deal with this is to ensure that all family caregivers are provided with good quality, timely information and resources from reputable sources

• Information needs to be presented in easy to understand language which can be translated into community languages (when applicable and possible)
Introduction

The information in this guide is useful if the person you are caring for has been told they have dementia or Alzheimer's disease.

People with dementia or Alzheimer's disease are not able to remember things as well as before. Over time their memory will get worse. They may get easily confused about simple things such as what time they should take their medicines or what their medicines are for. They may forget what their doctor or pharmacist told them about their medicines. It will be hard for them to learn how to do new things.

These changes happen because part of their brain has been damaged by disease. Alzheimer's disease is a type of dementia. In the rest of this guide only the word dementia will be used.

If you are looking after someone with dementia, you will need to think about how you can help them to do some things in a different way, so that they can still take their medicines safely. This guide will give you some ideas that might help your family member keep taking the right medicines at the right time.

‘help your family member keep taking the right medicines at the right time.’
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Thank you

Are there any questions?


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