Identifying Needs, Burden and Distress of Carers of People with Frontotemporal Dementia compared with Alzheimer’s disease

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Understanding Dementia

Alzheimer’s disease (AD)

Frontotemporal Dementia (FTD)

The Impact on Supports for Carers
The Aim

Comparing carers of people with FTD and AD in the following areas:

- Needs
- Burden
- Depression and Anxiety
The Participants

- 30 Carers of people with FTD
- 30 Carers of people with AD

Participants were recruited through:

Alzheimer’s Australia WA, Ltd and key health professionals
# Carer Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>FTD Carers</th>
<th>AD Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Median 58.5</td>
<td>Median 67</td>
</tr>
<tr>
<td>Gender*</td>
<td>93% Female</td>
<td>70% Female</td>
</tr>
<tr>
<td>Relationship</td>
<td>94% Partner</td>
<td>77% Partner</td>
</tr>
<tr>
<td>Time Caring</td>
<td>5.6 years</td>
<td>5.1 years</td>
</tr>
<tr>
<td>Finances*</td>
<td>40% Satisfied</td>
<td>67% Satisfied</td>
</tr>
</tbody>
</table>
Person with Dementia Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Diagnosis of FTD</th>
<th>Diagnosis of AD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong>*</td>
<td>Median 64</td>
<td>Median 76.5</td>
</tr>
<tr>
<td><strong>Gender</strong>*</td>
<td>90% Male</td>
<td>47% Male</td>
</tr>
<tr>
<td>Date of Diagnosis</td>
<td>3.8 years</td>
<td>3.2 years</td>
</tr>
<tr>
<td>Living Environment</td>
<td>73% Community</td>
<td>83% Community</td>
</tr>
</tbody>
</table>
Measures

The two-hour interview included:

• Background and demographic details
• Cambridge Assessment of Need for the Elderly (CANE)
• Revised Memory and Behaviour Problem Checklist (RMBPCL)
• Zarit Burden Index (ZBI)
• Depression, Anxiety and Stress Scale (DASS)
Objective

Can we determine whether someone is caring for a person with FTD or AD by studying the following characteristics?

1. Needs
2. Burden
3. Depression and Anxiety
Results

1. Carers of people with FTD reported greater needs than Carers of people with AD

2. The level of burden, depression and anxiety did not significantly differ between the two groups
FTD Carers Identified Greater Needs

- Domestic assistance
- Meals/Food
- Finances
- Information

- Personal care
- Continence
- Social Company
- Daily Activities
Needs continued...

- Psychological
- Communication
- Behaviours
- Preventing self-harm

- Protection
- Information for Carers
- Support for Carers
Support

- FTD Carers required more informal and formal help than AD Carers
- FTD Carers received greater informal help than AD Carers
- The amount of formal help was equal across groups
Behavioural Differences

Carers of People with FTD reported:

• A greater frequency of disruptive behaviours
• A greater negative impact and reaction to these behaviours
• The carer’s perception influence
• The gender influence
Predictors of Carer Distress

Can we predict Carer Distress using the following?

- Diagnosis
- Relationship to care recipient
- Length of time caring
- Carers physical health
- Level of burden

Yes, in combination, these factors accounted for a significant 49% of the contributing factors associated to carer distress.
Limitations

• RMBPCL and FTD presentation
• Carer only rating scale
• Carer’s current access to support and education
Implications

1. Awareness of the impact of different types of dementia and the subsequent impact on carers
2. Interventions for carers including a specific FTD Carer Support Group
3. Comprehensive needs assessment
4. Exploring depression and anxiety in FTD carers
Summary

1. Carers of people with FTD reported greater needs than Carers of people with AD.

2. FTD Carers required more informal and formal help.

3. Carers of People with FTD reported a greater frequency and emotional impact of disruptive behaviours.

4. We are still exploring what factors contribute to carer distress.

5. Remember the impact of the carer characteristics on their perception of needs, burden, depression and anxiety.
The Future

• To further develop the FTD Carer Support Group

• Dedicate services for FTD Carers and People diagnosed with FTD

• Promote community awareness

• Further research
Thank You!