Anticipatory Grief in Carers of People with Parkinson’s Disease

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Introduction

Anticipatory grief is the process of experiencing normal phases of bereavement in advance of the loss of a significant person. In advanced disease, people with Parkinson’s disease (PD) experience many disabling symptoms such as inability to perform activities of daily living, dementia, and sometimes personality changes such as aggression. This can lead to high burden in the carers. Caring for someone with a long-term progressing illness, such as dementia or cancer, may cause anticipatory grief. However, this phenomenon hasn’t been widely studied in relation to PD.

Objectives

1. To demonstrate the occurrence of anticipatory grief experienced by caregivers of people with PD.
2. To explore how this grief relates to caregiver burden and caregiver depression.

Methods

Data Collection
- Surveys were distributed to family carers of people with advanced PD (i.e. Hoehn & Yahr stages 3-5).

Setting
- Two Movement Disorder clinics in Cork

Instruments
- A demographic survey, and 3 validated questionnaires:
  - Anticipatory Grief Scale (AGS)
  - Zarit Burden Interview (ZBI)
  - Geriatric Depression Scale (GDS)

Findings

1. Demographics: Carers

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Sex: 20 S</th>
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</thead>
<tbody>
<tr>
<td>&lt;40</td>
<td>2</td>
</tr>
<tr>
<td>41-60</td>
<td>8</td>
</tr>
<tr>
<td>61-70</td>
<td>6</td>
</tr>
<tr>
<td>&gt;70</td>
<td>8</td>
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</tbody>
</table>

2. Occurrence of Anticipatory Grief

- Levels of anticipatory grief were high across the sample (M=71.5; SD=17.0; Sample Range=38-102; Scale Range =27-135).
- This is similar to previously reported mean scores of carers for people with dementia (M=70.11; SD=14.78).4

3. Relationship between Anticipatory Grief and Carer Burden and Depression

- Carers experiencing higher care burden had higher levels of anticipatory grief (r=0.75, n=25=8.433, p<0.015).

4. Relationship between Anticipatory Grief and Demographic Variables

Formal/Informal Support
- There was no significant difference in AGS between those receiving or not receiving formal support (z=-.064, p=.949), or informal support (z=-.134, p=.794).

Health Status
- There was a significant negative correlation between AGS and carers’ perceived health of the person with PD (r=0.43, n=25, p=.05).
- Those reporting their loved ones’ health as worse had higher anticipatory grief levels.

Quality of Care
- There was no significant relationship between AGS and carers’ rating of their loved ones’ quality of care (r=0.167, n=25, p=.483).

Behavioural and Psychological Symptoms
- Carers were asked the frequency with which their relative displayed certain behaviours and symptoms. The relationship with Anticipatory Grief was significant in two cases, see below:

<table>
<thead>
<tr>
<th>Behaviour/Symptom</th>
<th>Correlation with AGS</th>
</tr>
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<tbody>
<tr>
<td>Agitation</td>
<td>.467*</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>.444*</td>
</tr>
<tr>
<td>Memory Problems</td>
<td>.347</td>
</tr>
<tr>
<td>Verbal aggression</td>
<td>.147</td>
</tr>
<tr>
<td>Irritability</td>
<td>.113</td>
</tr>
<tr>
<td>Physical aggression</td>
<td>.100</td>
</tr>
<tr>
<td>Delusions</td>
<td>.040</td>
</tr>
<tr>
<td>Inappropriate/embarrassing behaviour</td>
<td>.025</td>
</tr>
</tbody>
</table>

*Significant at p<0.05

Conclusions

Carers of people with advanced PD experienced anticipatory grief. Its occurrence and severity was similar to that experienced by carers of people with dementia.

Anticipatory grief was also related to higher care burden and depression.

Risk factors, such as carers’ perception of poor health of their relative, and behaviours such as agitation and hallucinations, should be monitored to facilitate early interventions to combat anticipatory grief in PD carers.

Overall, to improve health outcomes of bereavement, the focus should include the period both before and after the death of a loved one.

References


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