“Sadness, frustration, angry. Hate this stupid disease!!!!”:
Contexts surrounding psychological mistreatment and neglect by caregivers to people with dementia

Kylie Meyer, PhD & C. E. Z. Pickering, PhD, RN

Introduction

• One-half of family caregivers to people with dementia participate in elder mistreatment

• Psychological mistreatment (e.g., yelling/shouting) and neglect (e.g., skipping care) are the most common types of mistreatment done by caregivers

• Very little is known about the lived experience of caregivers who engage in mistreatment behaviors

• **Purpose:** In this study, we examine caregiver behaviors and emotions surrounding a mistreatment event

Methods

• Family caregivers to people with dementia completed daily diaries twice a day for 21 days (N=50)

• When a caregiver indicated psychological mistreatment or neglect occurred, they were asked:
  1) What they were doing when the mistreatment event occurred; and
  2) How they felt when the event occurred

• Text responses were analyzed using content analysis
  - To accommodate the longitudinal nature of the data, we report caregivers as the unit of analysis
  - Responses could be coded in more than one way

Participants

• The average caregiver in this sample was a non-Hispanic (85%) woman (93%) who was caring for a parent (60%) and was 53 (+/- 11) years of age

• 64% (32) of caregivers committed psychological mistreatment at least once during the study period

• 50% (25) committed neglectful care at least once during the study period

Results

What was occurring when psychological mistreatment took place? (n=32)
(per cent of caregivers reporting each situation)

<table>
<thead>
<tr>
<th>Emotion/Experience</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The caregiver was reacting to a behavioral symptom of dementia</td>
<td>43.8%</td>
</tr>
<tr>
<td>The caregiver was struggling to perform a care task (issue non-specified)</td>
<td>43.8%</td>
</tr>
<tr>
<td>The caregiver described being inconvenienced by something the care recipent did</td>
<td>26.1%</td>
</tr>
<tr>
<td>The caregiver was trying to provide care but recipient refused</td>
<td>21.9%</td>
</tr>
<tr>
<td>The caregiver was hurt or insulted by something the recipient did or said</td>
<td>18.8%</td>
</tr>
</tbody>
</table>

Results (cont.)

What was occurring when neglectful care took place? (n=25)
(per cent of caregivers reporting each situation)

<table>
<thead>
<tr>
<th>Emotion/Experience</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The caregiver was trying to provide care but recipient refused</td>
<td>43.5%</td>
</tr>
<tr>
<td>The caregiver was prioritizing other care needs</td>
<td>30.4%</td>
</tr>
<tr>
<td>The caregiver was responding to a behavioral symptom</td>
<td>21.7%</td>
</tr>
<tr>
<td>The caregiver was attempting to meet their own needs</td>
<td>17.4%</td>
</tr>
<tr>
<td>The caregiver described being too tired to provide care</td>
<td>17.4%</td>
</tr>
</tbody>
</table>

Discussion

• Psychological mistreatment and neglect by caregivers to people with dementia are contextually unique events

Contexts surrounding psychological mistreatment

• Psychological mistreatment often occurs with triggering events, and could be described as reactionary

• High-arousal emotions were common in cases of psychological mistreatment

Contexts surrounding Neglect

• The contexts surrounding of neglect are more nuanced. In many cases, caregivers are simply unable to reasonably administer care, or do so and meet their own needs

• Caregivers who commit neglect appear to be drained, and were adamant about expressing their sense of exhaustion

Implications: Distinctions have implications for elder mistreatment prevention by family caregivers:

• Emotional regulation training, for example, may be more effective at preventing psychological mistreatment

• Respite opportunities, so tired caregivers can take a break, may be more effective for preventing neglect