EXPLORING THE FEELINGS OF GUILT OF GREEK-CYPRIOT FAMILY CAREGIVERS PROVIDING CARE TO PEOPLE WITH DEMENTIA

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INTRODUCTION

The rapid demographic changes of contemporary societies

→ Resulted in a dramatic increase in the aging population

Expansion of the proportion of people with **DEMENTIA**

→ Represents a major public health challenge (Prince et al., 2013, Kim et al., 2012, Plassman et al., 2007, Qiu et al., 2007)

**Most common forms of Dementia:**
- Alzheimer Disease (75% – 85%)
- Vascular
- Parkinson's
- Lewy body
- Pick’s disease (Kim et al., 2012, Redfern and Ross, 2006, Dupuis et al., 2004).
DEMENTIA

- Acquired, usually irreversible syndrome (Redfern and Ross, 2006, Dupuis et al., 2004)

- Regarded as a disease of old age → Increasing in incidence over the age of 65 (Hatfield et al., 2009, Cumming, 1995)

- Characterized by gradual deterioration of intellectual impairment (Paterson and Pond, 2009, van Houta et al., 2000)

- Affects language, memory, emotion, personality, concentration, personal judgment (Burns and Iliffe, 2009,, Coon et al., 2003)

→ Influence the person’s ability to perform normal daily life activities (Geerlings et al., 2005, van Houtven and Norton, 2004).
45 million of people with dementia globally → 60% live in low and middle income countries (ADI, 2013)

2/3 of individuals with dementia are female (Alzheimer Association, 2012, Kim et al., 2012)

By 2040:

75 million of people with dementia worldwide (ADI, 2013)

Cyprus → Exact number of individuals with dementia is unknown

→ Inadequate record of annual dementia cases (Eurostat, 2012).
The provision of unpaid assistance and support to family members or acquaintances with physical, psychological or developmental needs for more than 20 hours daily (Campbell et al., 2008, Cohen et al., 2002, Hagedoorn et al., 2002).

Caring is a challenging and difficult role, especially for the family caregiver who bears major responsibility for the person’s welfare (Campbell et al., 2008, Whitlatch and Noelker, 2007, Pearlin, 1992).
PROVISION OF CARE

- Most of the individuals with dementia live in the community

  → Depend on family members for assistance (children, spouse and others) (Neil and Bowie, 2008, Ulstein et al., 2007, John et al., 2001)

NEED OF CARE → Evolves constantly over time, requiring advanced planning, monitoring, coordination, associated with significant caregiver strain (Etters et al., 2008, Ruder, 2008)

  → Family caregivers experience increased physical and psychological burden (Zarit and Femia, 2008, Aggarwal et al., 2003, Greenberger and litwin, 2003, Zarit et al., 1980).
FEELING OF GUILT

- **GUILT** refers to an individual’s unpleasant or dysphoric feeling, arising with the recognition that one has violated a personally moral or social standard (Martin et al., 2006, Boye et al., 2002).

- Culturally sensitive emotion (Bierbrauer, 1992).

- Different people, have different degrees of proneness for feeling guilt in given situations (Abe, 2004, Tangney, 1996).

- **Common sources of Guilt** ➔ Aggressive, hostile behaviours and a feeling of moral inadequacy (Brodaty, 2007, Baumeister et al., 1994).
FAMILY CAREGIVERS’ GUILT

- Guilt has been considered as a main emotion for family caregivers, which may exacerbate their emotional burden (Boyce et al., 2002).

- Significant factor in determining the caregivers’ Quality of Life (Cooper et al., 2008, Coon et al., 2003) and the Quality of care given (Brodaty, 2007 και Ankri et al., 2005).

- Negative implications on the caregivers’ performance and their confidence (Gallagher et al., 2008, Gonyea et al., 2008).

→ Negative indicator of the willingness to continue in the family caregiving role (Brodaty, 2007, Spillers et al., 2008, Zarit et al., 1980).
FAMILY CAREGIVERS’ FEELING OF GUILT

Factors that may generate guilt:

- Fail to fulfill their obligations as caregivers (Ghatavi et al., 2002, Kasuya et al., 2000)
- Loss of self-control (Velone et al., 2007)
- Behaved poorly towards the patient in the past (Oyebode, 2003, Zarit et al., 1980)
- Devote time for themselves for leisure or other activities (Oyebode, 2003)
- Placement of their relative in a long term care institution, due to inability to continue offering adequate care (Bell et al., 2001, Dellasega, 1991).
First research study in Cyprus exploring feelings of guilt of the family caregivers providing care to individuals with dementia.

May contribute to a more comprehensive understanding of the emotional and behavioural consequences of guilt.

Development of effective psychoeducational interventions aimed at reducing caregivers’ distress.
To explore the factors associated with the feelings of guilt of the Greek – Cypriot family caregivers providing care to people with dementia
METHODOLOGY

DESIGN
Cross-sectional, Descriptive and Correlational study

SAMPLE
128 family caregivers (Greek – Cypriot) providing care to people with dementia living in an urban area of Cyprus
→ N=95 Community, N=33 Long-term care institutions

DATA COLLECTION
Lasted 8 months (June 2012 – January 2013).
INCLUSION CRITERIA

- Primary family caregivers providing care to their relative with dementia, living either at home, or in a long term care institution (period > 6months, at least 2 hours/day)
  - Have the most frequent contact with the patient
  - Principal responsibility for decision making regarding daily life issues
- Aged over 18
- Able to provide an informed consent
- Ability to read and understand the Greek language.
RESEARCH INSTRUMENT

1. «Caregiver Guilt Questionnaire – CGQ» → 22 Likert scale statements/items (Losada et al., 2010)

2. Socio-demographic characteristics

- Self-completed questionnaire (≈10’ to be completed)

- Approval obtained to use the scale.
ETHICAL CONSIDERATIONS

- Ethical approval by the Scientific Ethical Committee of the Ministry of Health, Cyprus

- All participants received
  - Written information regarding the purpose of the study and the choice to withdraw at any time
  - Informed consent
  - Anonymity and confidentiality were guaranteed

- Permission obtained by the nurses in charge of the ward units and by the managers of the institutions.
<table>
<thead>
<tr>
<th>FACTORS OF THE CGQ</th>
<th>ITEMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Guilt about behaving wrongly towards the patient</td>
<td>2, 10, 11, 12, 14</td>
</tr>
<tr>
<td>2 Guilt about failing to meet the challenges of caregiving</td>
<td>5, 8, 9, 21, 22</td>
</tr>
<tr>
<td>3 Guilt about neglecting other relatives and devoting time to themselves</td>
<td>1, 3, 4, 7, 15, 16</td>
</tr>
<tr>
<td>4 Guilt about having negative feelings towards other people</td>
<td>17, 18, 19, 20</td>
</tr>
<tr>
<td>5 Guilt about providing inadequate care</td>
<td>6, 13</td>
</tr>
</tbody>
</table>
## RELIABILITY

### Internal Consistency CGQ

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>TOTAL</th>
</tr>
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<tbody>
<tr>
<td>Cronbach's alpha</td>
<td>0.86</td>
<td>0.87</td>
<td>0.87</td>
<td>0.86</td>
<td>0.59</td>
<td>0.93</td>
</tr>
</tbody>
</table>
RESULTS
SOCIO-DEMOGRAPHIC CHARACTERISTICS

Gender

- Male: 75.8%
- Female: 24.2%

Was it your decision to undertake the role of the caregiver?

- Yes: 94.5%
- No: 5.5%
RESULTS

Demographic Characteristics

Place of patient’s residence

- Home: 74.2%
- Institution: 25.8%
RESULTS

Demographic Characteristics

- Partner: 0.8%
- Brother: 0.8%
- Sister: 2.3%
- Son: 7.8%
- Other: 17.2%
- Spouse: 27.3%
- Daughter: 43.8%

Values are percentages.
## Correlation of socio-demographic data in relation to Guilt

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<thead>
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<th>VARIABLE</th>
<th>GUILT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MEAN</td>
</tr>
<tr>
<td>Relationship of the family caregiver to the patient</td>
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<tr>
<td>Spouse</td>
<td>21.63</td>
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<tr>
<td>Son</td>
<td>28.80</td>
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<tr>
<td>Daughter</td>
<td>31.63</td>
</tr>
<tr>
<td>Other</td>
<td>29.91</td>
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<tr>
<td>F</td>
<td>3.446</td>
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<tr>
<td>p-value</td>
<td>.019</td>
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</tbody>
</table>

### Was your decision to provide care?

<table>
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<th>GUILT</th>
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<tr>
<td></td>
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<tr>
<td>YES</td>
<td>27.64</td>
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<tr>
<td>NO</td>
<td>42.29</td>
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<td>-2.563</td>
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<td>p-value</td>
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### Place of the patient’s residence

<table>
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<th></th>
<th>GUILT</th>
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<tbody>
<tr>
<td></td>
<td>MEAN</td>
</tr>
<tr>
<td>Home</td>
<td>25.80</td>
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<tr>
<td>Institution</td>
<td>36.06</td>
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<td>-3.532</td>
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<td>p-value</td>
<td>.001</td>
</tr>
</tbody>
</table>
RESULTS

Socio-demographic data found NOT to have significant relation with Guilt

- Gender of caregiver \( (p=0.723) \)
- Marital status \( (p=0.625) \)
- Occupation \( (p=0.153) \)
- Educational Level \( (p=0.458) \)
- Patient’s Diagnosis (Alzheimer or other form of dementia) \( (p=0.216) \)
- Age \( (p=0.483) \).
Factor 1 - Guilt about behaving wrongly towards the patient
- Decision of the family caregiver to provide care (p=0.003)

Factor 2 - Guilt about failing to meet the challenges of caregiving
- Marital status (married) (p=0.029)
- Place of the patient’s residence (p=0.001)
Correlation of socio-demographic data in relation to the factors of the CGQ

Factor 3 - Guilt about neglecting other relatives and devoting time to themselves

- Occupation (p=0.002)
- Relationship of the family caregiver to the patient (p=0.000)
- Educational level (p=0.037)
- Place of patient’s residence (p=0.002).
LIMITATIONS

- **Convenience Sample** → Limits generalizability of the results

- Feelings of guilt explored simultaneously in 2 groups →
  Difficult to attribute the exact factors giving rise to guilt

- **Restricted sample size in the 2\(^{nd}\) group** (caregivers providing care to people in institutions)

- Use of **structured instrument** → Did not allow the family caregivers’ free expression.
CONCLUSIONS

- Guilt is a common phenomenon experienced by family caregivers providing care to people with dementia
- Guilt is correlated with the characteristics of the caregiver
- Acknowledge the caregivers’ guilt and needs → Help them to adjust their expectations and standards
  → Development of community psychosocial support, aiming to reduce the caregivers’ guilt.
RECOMMENDATIONS

- Future studies:
  - Use additional research instruments → Explore other aspects of emotional burden
  - Investigation of additional independent variables → Study their correlation with guilt
  - Explore the usefulness of CGQ in other populations

- Intervention research → To help family caregivers to acknowledge guilt feelings → Determine ways to support them to reduce guilt.
THANK YOU

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