THE EMERGING ROLE OF THE INFORMAL SUPPORTER IN THE CARE OF PATIENTS AFFECTED BY CANCER

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Conflict of Interest

President of the European Oncology Nursing Society

Received honoraria from Amgen, Takeda, Medscape, MSD
The case of “informal caregivers”...
The concept of informal caregiving

Informal caregiving is broadly defined as providing personal care, assisting with medical care, performing household tasks, arranging for outside services, visiting regularly, or providing assistance with coping by a person who is unpaid (Kim et al 2009).

The role of the informal caregiver is usually assumed by a relative or friend who may or may not live in the same household as the person with cancer who requires care.
INTRODUCTION

The likelihood of a family member assuming the role of a caregiver is strengthened by the shift towards community care for patients with cancer, which has resulted in transferring responsibility for day-to-day care of patients to their family members...
Health systems are shifting...

Around the world we are witnessing ground breaking health reforms: ...the transition from a provider and procedure focused system to one that puts the **patient at the centre of care**...
Patient-centered care

Can be defined as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values.”
...in this context the critical role that family caregivers play in patient satisfaction and health outcomes is acknowledged...
What the numbers tell us..?

An estimated 4.6 million people in the United States care for someone with cancer at home (Institute, 2015). Even in countries with a well-developed supply of formal long term care, the number of family caregivers is estimated to be at least twice as large as the formal care workforce (Hoffman and Rodrigues, 2010)...

Estimates also suggest that the economic value of unpaid informal care - as a percentage of the overall cost of formal long-term care provision – in European Union Member States ranges from 50% to 90% (Triantafillou et al., 2010)...

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PROF. ANDREAS CHARALAMBOUS
Cancer Caregiving in Europe

Recent data from the EUROFAMCARE (Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage, and Usage) and SHARE (Survey of Health, Ageing, and Retirement in Europe) studies estimate that approximately 19 million individuals are providing care to an older individual in Europe.

EUROFAMCARE. Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage, and Usage. Available at: http://www.uke.de/extern/eurofamcare/

SHARE program website. Available at: http://www.share-project.org/

A trend that is likely to continue...

Treatments are provided in the ambulatory setting (including the home setting)
Patients live longer (but with long-term consequences of the treatment)
Limited healthcare resources
WHAT DOES THE EXPERIENCE OF CARE ENTAILS...?

The role of the caregiver

◦ Demanding and challenging

Caregiver’s responsibilities

◦ Medical, emotional and practical domain
◦ Different levels of care

Need to cope with:

◦ the patient’s symptoms and other problems
◦ their own difficulties of dealing with the patients’ condition
◦ their own feelings of loss and isolation (Ullgren et al 2018).
CARING ISSUES

The caregiving role often entails
- assuming the responsibility for communicating with healthcare professionals
- managing symptoms
- administering medications
- assess the response to therapeutic interventions
- recognize possible deterioration in physical status
- performing medical or nursing treatments, and handling patient behavioral problems and emotional reactions

All of these issues are a potential source of burden and depression...
SOCIAL AND FAMILY ISSUES

The prioritization of home care demands

Reprioritization of responsibilities related to child care and employment

The negotiation and renegotiation of factors related to familial relationships (e.g. role changes).
How family caregivers of cancer patients manage symptoms at home: A systematic review

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ABSTRACT

Introduction: Cancer affects not only the patient, but also the whole family, especially when a member of the family assumes the role of the family caregiver. This puts an additional emotional, social and financial strain on the family caregivers. Family caregivers of cancer patients are actively involved in the care provided at the home setting through various ways including practical tasks, symptom management and care coordination. The focus

Can be perceived as a stressful experience causing:
- Caregiver burden
- Psychosocial burden
- Psychiatric morbidity
- Life changes
- Lower quality of life
- Physical problems (e.g. sleep disturbances, fatigue, vulnerability to infections)
- Influences health caring behaviours

Caregiving and Screening

Evidence show that caregiving of a person with a chronic disease can also be a contributing factor to poor screening adherence.

Caregiving has been identified as a significant factor that can lead to poor utilization of health care services in the early stages of BC (Kinnear et al. 2010), informal carers may be less likely to meet their own health needs, may face higher allostatic load levels and have higher levels of mortality and morbidity as they age (Sheets et al. 2014).

These studies emphasize on carers’ impaired health behaviors, such as neglecting their own health care appointments and non-seeking cancer screening tests compared to non-carers (Son et al. 2011).
PROLEPSIS PROJECT WEBSITE LAUNCH

The Erasmus+ funded "Proleipsis" Project is pleased to launch its new website https://proleipsis.eu.

The project aims is to create a methodology and relevant contents extending informal carers’ knowledge regarding the impact of their prevention avoidance behavior on BC development and promoting their preparedness to engage in such behaviors.

While the outcome of breast cancer (BC) treatment largely depends on the timing of its detection and the national health systems throughout Europe follow the EU’s recommendations for the provision of mammography screening to detect BC in an early stage (http://ecb.euro.looking.eu/recommendations), women’s adherence to screening programmes is relatively poor. The average attendance in the EU/laws below the standard acceptable level (is 70% (Persy et al. 2016).

Caregiving of a person with a chronic disease can also be a contributing factor to poor screening adherence. Women who assume the role of the informal care face additional challenges in engaging in health promotion practices such as BC screening. Explicitly, studies on carers’ health behaviors stress the presence of impaired health behaviors, such as neglecting healthcare appointments, eating a poor-quality diet.

The specific objectives of the project are:

1. To create a methodology and relevant contents extending informal carers’ knowledge regarding the impact of their prevention avoidance behavior on BC development.
2. To educate and enhance them to assume control over this disease through adopting and maintaining changes in their lifestyle and living practices. These include modification of their lifestyle habits, self-monitoring, self-assessment and reinforcement of positive behaviors as well as encouragement of use of preventive BC services.
3. To develop a personalized mobile application (i.e. personal characteristics, needs and preferences), which will support informal carers to better manage self-care and behavior change in illness prevention.

As an additional tool, will be produced the handbook for educators working with informal and formal education and healthcare professionals working with women’s health promotion on how to use the app in health-literacy reinforcement programmes targeting not only informal carers but women’s health in general.

The handbook will be an e-book containing practical suggestions and guidelines for the two different target groups which will be based on the lessons learnt through the previous project actions.

The programme, currently in its first phase, is developed in partnership with 5 European partners, namely Technologio Panepistimio Kypros (Cyprus); Andani & non solo Società Cooperativa Sociale (Italy); Portincare+C – Associação Cuidadores de Portugal (Portugal); Singulariafugia (Greece); Europa Donna – Cyprus Breast Cancer Forum (Cyprus)

NOTES TO EDITORS

• To find out more about the PROLEPSIS project and to get involved in the activities please follow the link https://proleipsis.eu/.
• PROLEPSIS is co-funded by the European Commission under the Grant Agreement: nº 2019 – 1 – CY01-KA204-038266
A study on the burdensome and depressive experience of caring...
AIM OF THE STUDY

To discuss caregivers’ experiences in symptom management and to briefly describe the differences in the experience of care in three different caregivers’ groups, namely:

- cancer, dementia and schizophrenia

Exploration of differences in:
- Caregiver burden
- Psychiatric morbidity in the form of Depression
"Depression"

- in family caregivers is a specific emotional reaction to the stress of caregiving.
- It is described as a pathological alteration of a person’s state of mind and a decline in one’s mood that ends in sadness, accompanied by different vegetative and emotional symptoms and signs, related to thinking, behavior, and life rhythms, which tend to continue over a long period.
The “burden of caregiving”

- is a complex construct that challenges simple definition and is frequently defined by its impacts and consequences on caregivers. In addition to the emotional, psychological, physical, and economic impact, the concept of burden of care involves subtle but distressing notions such as shame, embarrassment, feelings of guilt, and self-blame.
METHODS

Design

- cross-sectional descriptive and correlation study
- Total Sample 410 (RR 75%)
- Alzheimer’s disease were 172 (RR = 86%), Schizophrenia, 113 (RR = 57%) and Cancer, 130 (RR = 86.6%).

The eligibility criteria for the caregiver

- the absence of mental or physical disability, being older than 20 years, speaking Greek, and having the most frequent contact with the patient and the greatest responsibility for at least 1 year
a) CAREGIVER BURDEN INSTRUMENT
- Greek version of the Zarit burden inventory. A self-administered instrument with 22 items, which explores negative effects on the caregiver, in relation to physical and mental health, social activities, and economic resources.

b) CAREGIVER LEVEL OF DEPRESSION
- The Greek version of the Center of Epidemiological Studies Depression (CES-D) Scale, validated in previous studies was used to assess the caregiver’s emotional well-being.
- The CES-D Scale is a self-report scale that consists of 20 items representing major symptoms in the clinical syndrome of depression.
RESULTS
<table>
<thead>
<tr>
<th>Caregiver variable</th>
<th>Alzheimer’s Disease</th>
<th>Schizophrenia</th>
<th>Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), y</td>
<td>56.8 (13.3)</td>
<td>56 (15.0)</td>
<td>50.6 (13.4)</td>
</tr>
<tr>
<td>Male</td>
<td>40 (23)</td>
<td>30 (26.5)</td>
<td>59 (45.4)</td>
</tr>
<tr>
<td>Female</td>
<td>113 (77)</td>
<td>83 (73.5)</td>
<td>71 (54.6)</td>
</tr>
<tr>
<td>Relation to patient, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>71 (41.3)</td>
<td>24 (21.4)</td>
<td>48 (36.9)</td>
</tr>
<tr>
<td>Son</td>
<td>10 (5.8)</td>
<td>10 (8.9)</td>
<td>19 (14.6)</td>
</tr>
<tr>
<td>Daughter</td>
<td>83 (48.3)</td>
<td>10 (8.9)</td>
<td>29 (22.3)</td>
</tr>
<tr>
<td>Parent</td>
<td>0</td>
<td>44 (39.3)</td>
<td>0</td>
</tr>
<tr>
<td>Sibling</td>
<td>0</td>
<td>21 (18.8)</td>
<td>20 (15.4)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (4.1)</td>
<td>3 (2.7)</td>
<td>14 (10.8)</td>
</tr>
<tr>
<td>Time since diagnosis, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1Y-4 y</td>
<td>61.1</td>
<td>17.7</td>
<td>93.1</td>
</tr>
<tr>
<td>5Y-10 y</td>
<td>36.6</td>
<td>18.6</td>
<td>6.9</td>
</tr>
<tr>
<td>&gt;10y</td>
<td>2.3</td>
<td>63.7</td>
<td>0</td>
</tr>
</tbody>
</table>
Burden and depression: mean values

In the total sample of caregivers, the mean burden was 42.3 with SD of 17.3, indicating that the total sample scored below the cutoff point.

When considering the 3 groups separately, the highest burden is found for Alzheimer’s disease caregivers (mean, 49.1), then for schizophrenia (mean, 37.6 [SD), and the lowest for cancer (mean, 37).

Alzheimer’s disease caregivers’ mean levels of burden were significantly higher compared with both cancer and schizophrenia means.
In the total sample of caregivers, the mean depression score was 18.4, indicating that on average, respondents scored above the cutoff point of 16 of the Depression Scale.

When considering the 3 groups of caregivers separately, in terms of depression, the highest level of depression is found for cancer caregivers (mean, 20.3), then follows schizophrenia (mean, 18.8), and finally Alzheimer’s disease (mean, 16.7).
One-way ANOVA showed also that there are significant differences ($P = .008$, $F = 4.8$) between the 3 caregiving groups in terms of depression.

Post hoc Tukey pairwise comparisons showed that there were significant differences between Alzheimer’s disease and cancer ($P = .006$), but not between Alzheimer’s disease and schizophrenia ($P = .215$) or between cancer and schizophrenia ($P = .498$).

Alzheimer’s disease caregivers’ mean levels of depression were significantly lower compared with cancer means.
<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>95% Confidence Interval for Mean</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Burden interview</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>172</td>
<td>49.1</td>
<td>17.1</td>
<td>46.6 - 51.7</td>
<td>0.0</td>
<td>83.0</td>
</tr>
<tr>
<td>Cancer</td>
<td>130</td>
<td>37.0</td>
<td>16.0</td>
<td>34.3 - 39.8</td>
<td>7.0</td>
<td>78.0</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>108</td>
<td>37.6</td>
<td>16.0</td>
<td>34.6 - 40.6</td>
<td>7.0</td>
<td>78.0</td>
</tr>
<tr>
<td>Total</td>
<td>410</td>
<td>42.3</td>
<td>17.4</td>
<td>40.6 - 43.9</td>
<td>0.0</td>
<td>83.0</td>
</tr>
<tr>
<td><strong>CES-D Scale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>168</td>
<td>16.7</td>
<td>10.9</td>
<td>15.0 - 18.4</td>
<td>0.0</td>
<td>45.0</td>
</tr>
<tr>
<td>Cancer</td>
<td>128</td>
<td>20.3</td>
<td>10.0</td>
<td>18.6 - 22.1</td>
<td>0.0</td>
<td>48.0</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>101</td>
<td>18.8</td>
<td>8.2</td>
<td>17.2 - 20.5</td>
<td>0.0</td>
<td>39.0</td>
</tr>
<tr>
<td>Total</td>
<td>397</td>
<td>18.4</td>
<td>10.1</td>
<td>17.4 - 19.4</td>
<td>0.0</td>
<td>48.0</td>
</tr>
</tbody>
</table>

Abbreviation: CES-D, Center of Epidemiological Studies–Depression.
The majority of the depressed caregivers were female (162 or 74%), were spouses (90 or 41.3%), followed by daughters/sons (78 or 35.8%) and siblings/parents (50 or 22.9%).

Among those depressed, the majority assumed the role of the caregiver for 2 to 4 years (68 or 31.1%), and the least depressed provided caring for 7 to 8 years (9 or 4.4%).
Stepwise multiple regression analysis showed that the level of education, time since diagnosis, and age significantly affected burden.

The disease group in which the caregiver belonged was found to be a significant factor, indicating that significant differences existed across the 3 disease groups in terms of burden, when examined by the aforementioned demographics, with higher levels of burden in the Alzheimer’s disease group.
## Table 3 • Stepwise Multiple Regression on Burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\beta$</th>
<th>Coefficient</th>
<th>$t$</th>
<th>$P$</th>
<th>$R^2$</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease group</td>
<td>-8.686</td>
<td>-7.781</td>
<td>&lt;.001</td>
<td>0.086</td>
<td>0.086</td>
<td></td>
</tr>
<tr>
<td>Caregiver education</td>
<td>-3.584</td>
<td>-6.170</td>
<td>&lt;.001</td>
<td>0.165</td>
<td>0.079</td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>1.313</td>
<td>2.853</td>
<td>.005</td>
<td>0.178</td>
<td>0.013</td>
<td></td>
</tr>
<tr>
<td>Caregiver age</td>
<td>-0.155</td>
<td>-2.327</td>
<td>.020</td>
<td>0.189</td>
<td>0.011</td>
<td></td>
</tr>
</tbody>
</table>
DETERMINANTS OF DEPRESSION

Stepwise multiple regression analysis showed that the caregiver’s level of education, gender, and relation to patient significantly affected depression.

The disease group in which the caregiver belonged was found to be a significant factor, indicating that significant differences existed across the 3 disease groups in terms of depression, when examined by the aforementioned demographics, with higher levels of depression in the cancer group.
Stepwise multiple regression examined which demographic variables significantly affect depression.

<table>
<thead>
<tr>
<th>Variable</th>
<th>( \beta ) Coefficient</th>
<th>( t )</th>
<th>( P )</th>
<th>( R^2 )</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver education</td>
<td>-0.758</td>
<td>-2.333</td>
<td>.020</td>
<td>0.040</td>
<td>0.040</td>
</tr>
<tr>
<td>Caregiver gender</td>
<td>3.487</td>
<td>3.181</td>
<td>.002</td>
<td>0.052</td>
<td>0.012</td>
</tr>
<tr>
<td>Relation to patient</td>
<td>-2.741</td>
<td>-3.789</td>
<td>.000</td>
<td>0.067</td>
<td>0.015</td>
</tr>
<tr>
<td>Disease group</td>
<td>2.356</td>
<td>3.426</td>
<td>.001</td>
<td>0.094</td>
<td>0.027</td>
</tr>
</tbody>
</table>
DISCUSSION

The results supported the hypothesis of disparities among the different groups of caregivers in terms of the levels of burden and depression.

Haley et al. (2001) aimed at comparing the caregiving stressors and psychological and health functioning between spousal caregivers of hospice patients with dementia versus lung cancer. The findings showed that, although caregivers of patients with dementia provided care for many more months, caregivers of patients with cancer provided many more hours of caregiving during a week.

Stetz and Brown (2004) aiming to compare cancer and AIDS patient caring found that both caregiver groups reported high levels of stress and depression, although cancer patient caregivers demonstrated higher social functioning when compared with the other group.
The results showed that family caregivers experience burden and depression regardless of the group of patients they care for. However, the type of the disease and consequently the nature of the care demanded by the disease appear to be the reason for variation in the expressed levels of burden and depression.

The highest levels of depression were found in family caregivers of patients with cancer, and then followed by caregivers for patients with schizophrenia.
What is the reason that family caregivers of patients with cancer experience higher levels of depression compared with the other 2 groups?

There can be numerous explanations of this finding based on the nature of the disease and what this entails. Caregiver depression may result from anticipatory grieving of losses resulting from the patient’s illness as well as the eventual death of the patient due to cancer.

However, grief is often misdiagnosed as clinical depression...
Another possible interpretation of the reported levels of depression is the fact that patients appear more depressed (due to their illness, bad prognosis or the anticipated death), which makes the experience of caregiving even more difficult...
Informal caregivers can experience depression and burden as a result of their caregiving role, therefore caregivers at risk should be identified timely and supported accordingly.
Take home message...

CLINICAL Implications
◦ HCP need to be alert and recognize early signs of depression in caregivers
◦ Empower caregivers in their caring role, by information and teaching how to cope with the problems of the disease and their own feelings

EDUCATIONAL Implications
◦ Strengthen family care in modules of cancer care of health care professional studies

RESEARCH Implications
◦ More robust methodologies, bigger samples, more intervention studies

SOCIAL Implications
◦ Provide caregivers the support they need as to maintain the normality in their own lives.
Selected further reading articles


Thank you…