Suffering in silence: The impact of cancer on caregivers

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Overview of talk

• Caregivers – who are they & what do we know so far?

• The impact of caring - Australia data: Partners & Caregivers Study
Who are the carers?

• “A carer is a family member, parent, partner, significant other, friend or neighbour who provides care on an unpaid basis”

• 2.6 million carers in Australia in 2009

• Compared to all carers, cancer caregivers are:
  – More likely to be female, partner or spouse, living with the person they care for
  – Significantly older
  – Less likely to be in labour force

*Carers NSW with the Carers Coalition. Reaching ‘Hidden’ Carers. Carers NSW, July 2001
ABS. Disability, Ageing and Carers, Australia: Summary of findings. Canberra: ABS, 2009
Background

- Past decade has seen a marked increase in the attention given to the work, financial, and psychosocial challenges confronted by partners (Jenewein et al., 2007; Kayser et al., 2007)

- Partners often expected to take on additional roles, provide emotional and practical support to patients, and engage in illness management tasks

- Despite partners’ efforts to manage cancer-related challenges, these may exceed their capabilities and result in feeling burdened (Grunfeld et al., 2004; Jenewein et al., 2007)
Physical, Psychosocial, Relationship, and Economic Burden of Caring for People With Cancer: A Review

By Afaf Girgis, BSc(Hons), PhD, Sylvie Lambert, PhD, Claire Johnson, RN, CM, PhD, Amy Waller, PhD, and David Currow, BMed, MPH, FRACP

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Abstract

The aim of this article is to provide an overview of the issues faced by caregivers of people diagnosed with cancer, with a particular emphasis on the physical, psychosocial, and economic impact of caring.

A review of the literature identified cancer as one of the most common health conditions in receipt of informal caregiving, with the majority of caregivers reporting taking on the role of caring because of family responsibility and there being little choice or no one else to provide the care. For some, caregiving can extend for several years and become equivalent to a full-time job, with significant consequent health, psychosocial, and financial burdens.

Having a better understanding of the critical and broad roles that caregivers play in the oncology setting and the impact of these on their health and well-being may assist health care professionals in supporting caregivers with these tasks and targeting services and interventions toward those most in need.
Impact of cancer on partners and caregivers

Physical health problems (eg, back pain, fatigue, loss of appetite)

Emotional problems and reactions (eg, anxiety and depression)

Social problems (eg, hard to concentrate at work, balancing multiple roles, difficulty to pay bills, change in employment status)

Burden related to responsibilities (eg, assisting with mobility, managing patient’s symptoms)

(Girgis et al., 2012; Braun et al., 2007; Carter & Acton, 2006; Dalton et al., 2007; Gauger et al., 2005; Hagedoorn et al., 2008; Jenewein et al., 2007; Kim & Spillers, 2009; Kim et al., 2007; Kim et al., 2006; Lewis et al., 2008; Matthews et al., 2003; Mellon et al., 2006; Papastavrou et al., 2009)
Background

- Partners experience psychosocial challenges analogous to those reported by patients diagnosed with cancer (e.g., shock, uncertainty, anxiety) (Girgis & Lambert, 2009)

<table>
<thead>
<tr>
<th>Patient Prevalence</th>
<th>Partner Prevalence</th>
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<tbody>
<tr>
<td>Anxiety - 10% to 50%</td>
<td>Anxiety - 16% to 56%</td>
</tr>
<tr>
<td>Depression – 4.5% to 50%</td>
<td>Depression - 10% to 52%</td>
</tr>
</tbody>
</table>

(Carlson et al., 2004; Meyerowitz & Oh, 2009; NBCC, 2003; Segrin et al, 2005; Zabora et al, 2001)
The Partners & Caregivers Study

- Longitudinal study of partners/caregivers of cancer survivors diagnosed with one of the 8 most common cancers in Australia (recruited via Cancer Registry)

Main aims:
- Describe changes in anxiety, depression, quality of life, and unmet needs and identify variables associated with these outcomes, over first 5 years post-diagnosis
- Describe relationship between cancer survivors’ and partners’ psychosocial outcomes
- Assess costs associated with caring for a person with cancer
The Partners & Caregivers Study

Multi-dimensional outcomes: Self-administered scannable survey

- Anxiety: Hospital Anxiety & Depression Scale
- Depression: Hospital Anxiety & Depression Scale
- Perceived needs: Supportive Care Needs Survey - Partners & Caregivers
- Quality of life: SF-12
- Coping: Brief Cope
- Social support: MOS Social Support Survey
- Caregiver burden, role involvement and financial strain
- Demographics, patient disease and treatment characteristics

6 months (n=547)
1 year (n=521)
2 years (n=442)
3.5 years (n=386)
5 years (n=210)

Time since cancer survivor’s diagnosis
Demographics (n=547; 44% consent; 83% returned survey)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>%</th>
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<tbody>
<tr>
<td>Gender: Female</td>
<td>70</td>
</tr>
<tr>
<td>Age: 60+</td>
<td>56</td>
</tr>
<tr>
<td>Country of origin: Australia</td>
<td>81</td>
</tr>
<tr>
<td>Marital Status: With partner</td>
<td>96</td>
</tr>
<tr>
<td>Relationship to cancer patient: Partner</td>
<td>90</td>
</tr>
<tr>
<td>Patient-Caregiver living arrangement: Together</td>
<td>92</td>
</tr>
<tr>
<td>Education: Primary school/secondary not completed</td>
<td>20</td>
</tr>
<tr>
<td>Secondary school</td>
<td>24</td>
</tr>
<tr>
<td>Trade, TAFE, University</td>
<td>55</td>
</tr>
<tr>
<td>Employment: Employed/student</td>
<td>49</td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>39</td>
</tr>
<tr>
<td>Household duties</td>
<td>10</td>
</tr>
<tr>
<td>Current Household Income: &lt;$500 pw</td>
<td>32</td>
</tr>
<tr>
<td>$500-$799 pw</td>
<td>21</td>
</tr>
<tr>
<td>$800-1,000 pw</td>
<td>14</td>
</tr>
<tr>
<td>&gt;$1,000 pw</td>
<td>20</td>
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</table>
Diagnosis of the cancer survivors (n= 1,453)

- Prostate: 27%
- Melanoma: 15%
- Breast: 15%
- Bowel: 12%
- NHL: 11%
- Lung: 10%
- Head & Neck: 7%
- Leukaemia: 2%
Anxiety at 6, 12 and 24 months

- 6 months:
  - Caregivers: 38%
  - Survivors: 24%
  - N caregivers = 540
  - N survivors = 1351
  - p < .001
- 12 months:
  - Caregivers: 31%
  - Survivors: 22%
  - N caregivers = 514
  - N survivors = 1246
  - p < .001
- 24 months:
  - Caregivers: 28%
  - Survivors: 20%
  - N caregivers = 422
  - N survivors = 1100
  - p < .001
Distressed Partners and Caregivers Do Not Recover Easily: Adjustment Trajectories Among Partners and Caregivers of Cancer Survivors

Sylvie D. Lambert, Ph.D. • Bobby L. Jones, Ph.D. • Afaf Girgis, Ph.D. • Christophe Lecathelinais, DESS de Mathématiques Appliquées
Who is at risk of chronic anxiety?

- **High avoidant coping** e.g., coping with cancer challenges by criticising themselves, refusing to believe that it has happened, or given up trying to deal with challenges (OR = 20.80 – 30.77)

- **Low emotional/informational support** i.e., did not have someone they can count on to listen when needed, someone to give you good advice, or someone to turn to for suggestions about how to deal with problems (OR = 0.48 - 0.56)

- **High interference** in daily activities due to their caregiving role (OR= 3.03-3.20)

- **High involvement in caregiving roles** - emotional support, household, and practical tasks (OR= 1.22-1.45)
• Review by Harrison et al. (2010) found that 20-40% of patients report at least one moderate/high unmet need.
% reporting at least one moderate/high unmet need by cancer type

- Colorectal
- Breast
- Prostate
- Melanoma
- Lung
- NHL
- Head & Neck
- Leukemia

% Sample

6 months, 12 months, 24 months
Top moderate/high needs at 6 months vs 12 months

Managing concerns about recurrence
Reducing stress for patient
Understanding the experience of the person with cancer
Findings more accessible hospital parking
Accessing info: treatment for decision making
Balancing own and patient needs
Obtaining best medical care for patient
Addressing fear about patient deterioration
Adjusting to changes in patient’s body
Addressing problems with sex life

% Sample
New moderate/high needs at 12 months

- Dealing with others not acknowledging impact on your life of caring for a person with cancer
- The impact that cancer has had on your relationship
- Looking after your own health
In past 7 days, how much did your caregiver role affect work/study productivity?

17% @ 6mths
11% @ 12mths
10% @ 2yrs

% of caregivers

No effect ←-------------------------------------→ Completely prevented
In past 7 days, how much did your caregiver role affect your ability to do regular activities? (eg shopping, work around house, exercising)

% of caregivers

22% @ 6mths
13% @ 12mths
7% @ 2yrs

No effect  → Completely prevented
Summary

• Anxiety, unmet needs & impact on productivity extend into and beyond the initial survivorship phase.

• Distressed caregivers do not easily recover. Caregivers maintained whatever level of anxiety reported at six months - a particularly concerning finding for those experiencing chronic anxiety.

• Chronic anxiety was predicted by: higher involvement in emotional support; household and practical roles; interference in daily activities due to caregiving role; and use of avoidant coping and lower emotional/informational support. Coping strategies and tangible support may assist caregivers.
Challenge

- How do we include partners/caregivers as part of the unit of care?
- How do we regularly screen for distress in partners/caregivers?
Thank You

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