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Who is the carer and who needs care? The impact of the caring role on the older family carers.

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6th International Carers Conference
Gothenburg, Sweden - September 2015

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Aim

To present a literature review on the impact of caring upon older family carers and guidelines for improving support to this population.

Presentation Outline

- Statistics
- Search strategy;
- Evidence of the impact of caring on the social life, mental and physical health of older family carers;
- Recommendations for support.

Family caring by older people

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- **In the UK, nearly a quarter of all carers are older people (65+).**
- **From 2001 to 2011:**

  - Aged 30-44: increased by 6%

  - Aged 60-74: increased 33.6%

  - Aged 75+: increased 39.5%

- **Carers of aged 50-64: more likely to be caring for more than one person.**
- **Spouses (chronic illnesses), children (learning disabilities) and grandchildren.**

(The Princess Royal Trust for Carers, 2011; White, 2013; Carmichael & Ercolani, 2014)

Family caring by older people

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- **Most intensive carers, longest hours (≥ 60 h/w, aged 70+) with no breaks, co-resident, caring for an older person of a similar age, providing personal care (ADL).**
  - **Personal care:** provided by adults with a physical disability and older people.
  - **Co-residing:** related to more personal care provision.
  - Indicators of more intensive caring -> useful for identifying those carers who most need support.
- **Older carers are overlooked and need to be supported.**

(Hellström & Hallberg, 2001; Vlachantoni, 2010; The Royal Princess Trust, 2011; Carmichael & Ercolani, 2014)

Literature review

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<table>
<tr><td rowspan="3">Search strategy

- to 2015</td><td colspan="4">Keywords - Combinations</td></tr>
<tr><td>OR</td><td>aged
ageing
aging
elder
elderly
older
senior</td><td>(informal)
(non-professional)
(non-formal)
(family)
(unpaid)
(spousal)</td><td>caregiver*
carer*
spouse*
couple*
husband*
wife
wives
spouse*</td></tr>
<tr><td colspan="4">Limits: English language and age group (≥45 years old).</td></tr>
<tr><td>Databases</td><td colspan="4">EMBASE OVID; MEDLINE OVID; PSYCHINFO OVID; CINAHL; ASSIA; Google scholar.

Total: 3,244 Duplicates: 235

Data screening (title and abstract): 1,081 possibly relevant</td></tr>
<tr><td>Included</td><td colspan="4">n = 599</td></tr>
</table>

Literature review

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- Epidemiology and general reports or reviews (n= 72);
- Mental Health, sleep and immunity (n= 129);
- Physical health and health promotion (n= 102);
- Interventions, service use and support (n= 181);
- Quality of life, social life, burden and well-being (n= 115);
- Others (n=494).

General aspects

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- **Older or ageing carers:** No clear age cut-off (45+, 50+, 60+, 65+).
- **Comparisons:** 1) older carers and age/sex match controls; 2) older carers and younger carers; 3) dementia and non-dementia; 4) spouses and others.
- Dementia, stroke, Parkinson's, cancer and intellectual disabilities.
- Earlier retirement and higher financial impact (60-65 years old).
- Depression and stress -> most frequently investigated.

(Schulz and Sherwood, 2008; Lee and Zurlo, 2014; Tartaglini et al., 2015)

Mental health, sleep and immunity

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- Poor mental health and higher risk for psychiatric morbidity.
- More physical impairment, lack of social support and greater conflict -> Poorer mental health.

Cognitive function

- 255 carers diagnosed with dementia: spouse's dementia onset -> 6x greater dementia risk - husband with higher risk.
- Worse cognitive performance than non-carers.
- Receiving help during with caring and better financial situation -> better cognitive function.

(Kochar et al., 2007; Norton et al., 2010; Butterworth et al., 2010; Al-Zahrani et al., 2015; Amer et al., 2015)

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Stress and Depression

- Care provision is stressful and increases risk for depression, specially in dementia carers -> greater mortality risk in short-time period.
- Care intensity and cared for problems -> role captivity (non-dementia) / domestic help -> stress.
- 81% of depressed carers not taking antidepressants.
- Less likely to be taking antidepressants than younger carers.

(Mui, 1995; Bookwala, Jamila Schulz, Richard, 2000; Bertrand, Clipp et al., 2005; Fredman and Saczynski, 2006; Valimaki et al., 2009; Fredman et al., 2010; Chou et al., 2010; Mausbach et al., 2012; Neri et al., 2012; Mausbach et al., 2013; Chow & Ho, 2014; Chong et al., 2014; Fredman et al., 2014; Litwin, Stoeckel and Roll, 2014; Dilworth-Anderson, 2015; Givens, et al., 2015; Luquesi et al., 2015)

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Stress and Depression

- **Causes of depression in older carers:**
  - Older age and female gender.
  - Caring for longer time with low social support and high burden.
  - High neuroticism, stress and role captivity.
  - Worse physical health.
  - Becoming a ADL carer.
  - Relationship with the cared for and his/her symptoms.
  - Few social ties and loneliness.
  - Exiting caring.
  - Low income.

(Bookwala, Jamila Schulz, Richard, 2000; Connell and Gallant 2003; Berkman et al., 2004; Ekwall, Sivberg and Hallberg, 2007; Chou et al., 2010; Neri et al., 2012; Litwin, Stoeckel and Roll, 2014; Masakazu, Yumiko and Mitsuru, 2014; Jaremka et al., 2014; Dunkle, et al., 2014; Luchesi et al., 2015; Steptoe, Shankar, and Rafnsson, 2015; Gantman, Selezneva and Gavrilova, 2015)

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Stress and Depression

- **Dementia carers** -> (role captivity and care recipient problematic behaviour) -> depression.
- **Depression** -> more sleep problems, poor appetite, risk of malnutrition, poorer health.
- **Depression** -> physical health and burden, decreased cellular immunity, more days of infectious illness.
- No relationships over time (6y) (depression and disability).

(Pruchno et al., 1990; Torres, McCabe and Nowson, 2010; von Kanel et al., 2014; Fredman et al., 2014; Bacon et al., 2015; Givens, et al., 2015)

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Sleep and immunity

- Overall worse sleep quality when compared with youngers.
- **Increased positive affect** -> better sleep, independently of negative affect.
- **Poor sleep quality** -> norepinephrine, inflammatory + pro-coagulant markers -> CVD morbidity, mostly in AD carers.

(Kiecolt-Glaser et al., 1991; Mausbach et al., 2006; von Kanel et al., 2006; Lovell & Wetherell, 2011; Dilworth-Anderson, 2015)

Mental health, sleep and immunity

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Immunity

- **Older people:** natural deregulation of immunologic system.
- **Low social support + more affected by cared for symptoms** -> greatest negative changes in immune function over time.
- **Higher stress** -> dysregulates multiple components of innate and adaptive immunity -> impaired control of latent viruses, exaggerated production of inflammatory mediators, premature and accelerated cellular aging, greater total cortisol output across the day, lower cell-mediated immune response to vaccination, impaired endothelial functioning when compared to older people non-carers / younger carers.

(Vedhara et al., 2002; Mausbach et al., 2007; Gouin, Hantsoo and Kiecolt-Glaser, 2008; Gouin, Hantsoo & Kiecolt-Glaser, 2008; Mausbach et al., 2010; Wong et al., 2013; Scheyer et al., 2014; Phillips, Vitlic, Lord and 2015)

Physical health and health perception

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Self-rated health

- 65% poor self-perceived health.
- **Better self-rated health** -> older carers who work and/or volunteer, female carers, increased self-efficacy.
- **Poor perceived health:** advanced age, anxiety, emotional strain, non-white wives.

(Mui, 1995; Rozario, Morrow-Howell and Hinterlong, 2004; Ducharme et al., 2007; Neugaard et al., 2008; Yamaki, Hsieh and Heller, Tamar, 2009; Valente et al., 2011)

Physical health and health perception

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Physical health

- **High levels of caring responsibility** -> poorer reported health.
- Arthritis, HBP, obesity, and activity limitations, backaches, insomnia and hearing problems.
- Around 93% at least one CI; 60.5% ≥ 1 CI; + CI -> advanced age, female, greatest overall time demands - more time on caring for others than for their own health.

(Scharlach et al., 1994; Yamaki, Hsieh and Heller, Tamar, 2009; Ji et al., 2012; Jowsey et al., 2013; Wang, Robinson and Carter-Harris, 2014; Dilworth-Anderson, 2015)

Physical health and health perception

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Physical health

- **Providing more ADL assistance (dementia)** -> extended physical illness or disability, unhealthy medical rating, or hospitalization.
- **Older carers:** at risk of a more rapid transition to frailty (especially 80+) and clinical manifestations of CVD.
- Lower frailty risk in when high positive affect.

(Shaw et al., 1997; von Kanel et al., 2006; Park-Lee et al., 2009; Jenkins, Kabeto, and Langa, 2009; Dilworth-Anderson, 2015)

Physical health and health perception

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Physical health

- **Older carers' WHO Surveys:** 26.9-42.5% respondents from high to low income countries reporting serious relative health conditions.
- **Longitudinal (8y):** 50.9% developed mobility limitations.
- **Female, low perceived social support** -> more comorbidities.
- **Loneliness:** more concurrent pain and fatigue and larger increases in symptom levels.
- **Access to extensive social ties** -> better health outcomes.

(Fredman et al., 2008; Neri et al., 2012; Shahly et al., 2013)

Physical health and self-care

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- **Better physical and mental health** -> better learning resources, health status, economic status.

Self-care

- Lower leisure-time exercise but no difference in physical activity.
- **Better health behaviours than youngers:** 86% of appropriate preventive health practices.
- **Good sense of control** -> better preventive health behaviours.

(Burton et al., 1997; Chang, Sarna and Carter, 2001; Connell and Gallant 2003; Matthews et al., 2004; Berkman et al., 2004; Fredman et al., 2006; Rabinowitz et al., 2007; Mugisha et al., 2013; Jaremka et al., 2014; Chen, Chen and Chu, 2015)

Support

- Initiatives to support older carers are needed, especially in **low-lower-middle income countries**.
- Older and relatively poor carers may benefit from programs to **reduce physical burden** -> need to adapt, recognise and reduce the burden on carers who themselves have **chronic illness**.
- Preparing resources and maintaining strong **social support** systems may **reduce loneliness** and **foster health status.**
- Improve the **social functioning of the person with dementia**, the **carer's perceptions** and the **carer's functional capacity**.

(Van Den Wijngaart, Vernooij-Dassen and Felling, 2007; Kim and Spillers, 2010; Ahn et al., 2012; Shahly et al., 2013; Jowsey et al., 2013)

Support

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- **Early identification/treatment of depression**, as well as interventions focusing on **improving QoL**.
- **Behavioural management therapy** and **physical activity** may improve symptoms of depression in dementia carers.
- **Targeting problematic behaviours** among dementia patients and addressing aspects of dementia care that improves **role captivity** may ameliorate depression.
- To preserve **carer's health**, maintain **recipient health** and **care quality.**
- **Couples** may need to be assessed **as a unit**, taking **gender** and **cultural considerations** into account, and additional resources.

(Clipp et al., 2005; Lavela and Ather, 2010; Lautenschlager et al., 2014; Loi et al., 2015; Givens, et al., 2015; Luquesi et al., 2015)

Support

- **Financial support**: financial and benefit's advice.
- **Regular breaks**: breaks should include access to high quality alternative care.
- **Recognition by health and care professionals:** carer awareness and involvement.
- **Physical and mental health:** physical health check/year (mental health screen) and support. Effective age specific methods of promoting mental **well-being** in order to reduce stress, anxiety, depression. **Appointments should be flexible** (home visits or alternative care provision if necessary).
- Suitable transport to take older carers to care homes and hospitals.

(The Princess Royal Trust for Carers, 2011; Steptoe, Shankar, and Rafnsson, 2015)

Support

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- **To promote wellbeing in the way most useful to carers** -> social connection, physical activity and the maintenance of lifelong learning -> reduce loneliness.

- **Training for safety and appropriate care.**

- **Planning for the future** : emergency card and emergency care schemes. including support to plan for the future.

- Help older carers integrate back into their communities (local groups, activities and volunteering opportunities among ex-carers).

- Support for death planning, counseling.

(The Princess Royal Trust for Carers, 2011; Steptoe, Shankar, and Rafnsson, 2015)

Conclusions

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- **Differences in results:** different conditions affecting the cared for, socioeconomic factors and different sample sizes.

- To consider specific characteristics of the care recipient and changes in the caring experience, support, burden, etc.

(Schulz and Sherwood, 2008; Lavela and Ather, 2010; Lovell and Wetherell, 2011)

Acknowledgements

- PhD Scholarship: CAPES Foundation and University of Nottingham.

- School of Health Sciences grant and Graduate School Travel Prize.
- Academic supervisors: Dr. Aimee Aubeeluck and Dr. Catherine Vass.

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Thank you

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