Economic and social policy implications associated with caring for people with chronic conditions

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- We model costs and benefits of caring for health conditions.
- We measure cost-effectiveness of chronic conditions and genomic medicine.
- Series of models on costs of informal caring.
- Using Survey of Disability, Ageing and Carers, we model #s of informal carers of various conditions, and costs of reduced workforce participation.
- Collaborate with community groups, health services and clinicians.
- Our research is used to advocate for policy to improve lives of families and carers.
- Policy advice on Childhood Cancer, SMA, Genetic eye diseases.
Carers NSW is the peak non-government organisation for carers in New South Wales (NSW).

Our goals are to:

• Be a leading carer organisation in which carers have confidence
• Actively promote carer recognition and support
• Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
• Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
• Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
• Continue to be a quality-driven, responsive and carer-focused organisation.
About Carers NSW

Who are carers?

• Provide care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

• This definition does not include:
  • paid care workers
  • formal volunteers
  • parents / foster carers / kinship carers

• 904,400 in NSW, including approximately 278,700 primary carers*

* 2015 Survey of Disability, Ageing and Carers
Reduced workforce participation among carers

Background

Carers NSW 2018 Carer Survey
Impacts of caring on workforce participation

- Research has highlighted the impact of lost wages and superannuation on carers, it has tended to generalise about carers rather than considering variation across different types of carers.

- Given the rise of chronic conditions due to advancements in medical care, pre-term births and population ageing, carers of people with chronic conditions are an increasing population.

- Analysis of specific conditions shows age-gender breakdown, and where to focus resources.
Model description

ABS Surveys of Disability, Ageing and Carers (SDACs) 2003, 2009 and 2012

Static ageing

Population, labour force trends

The 2015 Intergenerational Report

Socio-demographic including informal carers

APPSIM

Reweighted SDACs

Synthetic matching

STINMOD (Economic data)

2015 2020 2025 2030

Simulate economic impacts
Compared data on lost income of informal carers of people with chronic conditions, i.e. back pain, arthritis, cardiovascular disease, mental illness and the lost revenue to the government.

- ABS, SDAC 2003, 2009 and 2012, 15 to 64 years age group population.

The SDACs include:

- **demographics;** e.g. age, sex, family type, region and state of residence.
- **socioeconomics;** level and field of education, income, benefits.
- **labour force;** labour force participation, retirement, weekly hours of paid employment, reason for leaving the labour force (e.g. carer).
- **care responsibilities;** caring status (primary, other or non-carer), average weekly hours caring.

For main care recipients with (matched) primary carers:

- **health and disability variables;** long-term conditions, health status, type and extent of disability, support and care required.
Four synthetic datasets (for 2015, 2020, 2025 and 2030) representing the snapshots of:

- the informal carers leaving the labour force
- socio-demographic information on informal carers
- economic impacts of informal care provision (e.g. labour force participation, incomes, savings, welfare payments, taxes)
## Number of informal carers for top conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Disease code</th>
<th># Informal carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Back Pain</td>
<td>1303</td>
<td>78</td>
</tr>
<tr>
<td>Autism and Intellectual Disability</td>
<td>530,531,532</td>
<td>71</td>
</tr>
<tr>
<td>Mental Illness &amp; behavioral disorders</td>
<td>500, 511, 512, 521, 522, 595, 599</td>
<td>70</td>
</tr>
<tr>
<td>Depression</td>
<td>513</td>
<td>21</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1301</td>
<td>67</td>
</tr>
</tbody>
</table>
Carers by condition

(a) Arthritis

(b) Back pain

(c) Mental Illness

(d) Depression

Number of informal carers - Mental Illness

Number of informal carers - Depression

Carers by condition
Comparative costs of ID and ASD vs back pain

Modelled costs by condition

Intellectual Disability and Autism Spectrum Disorders

- Lost income
- Lost tax
- Increased Welfare

Back Pain

- Lost income
- Lost tax
- Increased welfare

$ million

2015 2020 2025 2030

Lost income  Lost tax  Increased Welfare

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Costs of mental illness

National costs of mental illness and depression

Depression

Mental Illness

Lost income
Lost tax
Increased welfare

$ million

2015
2020
2025
2030

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### National costs

National aggregated costs associated with early retirement due to informal caring, Australians aged 15-64 years, (in billions, 2015 $)

<table>
<thead>
<tr>
<th>Loss</th>
<th>Billions $ 2015 (95% confidence intervals)</th>
<th>Billions $ 2030 (95% confidence intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lost income</td>
<td>3.58</td>
<td>5.33</td>
</tr>
<tr>
<td></td>
<td>(3.40; 3.88)</td>
<td>(5.07; 5.70)</td>
</tr>
<tr>
<td>Lost tax payment</td>
<td>0.99</td>
<td>1.44</td>
</tr>
<tr>
<td></td>
<td>(0.93; 1.07)</td>
<td>(1.35; 1.55)</td>
</tr>
<tr>
<td>Increase in transfer/welfare payments</td>
<td>1.45</td>
<td>1.94</td>
</tr>
<tr>
<td></td>
<td>(1.42; 1.48)</td>
<td>(1.91; 1.97)</td>
</tr>
</tbody>
</table>
Replacement care

Formal services enabled carers to work

National Disability Insurance Scheme supports

- Enabled them to take a break: Agree (45%) vs. Disagree (55%)
- Given time for own health needs: Agree (50%) vs. Disagree (50%)
- Enabled them to work: Agree (60%) vs. Disagree (40%)

Aged care services

- Enabled them to take a break: Agree (50%) vs. Disagree (50%)
- Given time for own health needs: Agree (40%) vs. Disagree (60%)
- Enabled them to work: Agree (40%) vs. Disagree (60%)

Carers NSW 2018 Carer Survey
Current use of flexible working arrangements

- Carers leave
- Flexible start/finish times
- Work from home
- Job sharing
- Other
- None of the above

Carers NSW 2018 Carer Survey
Conclusions

• Demand for informal carers is projected to increase in the next 20 years

• Exiting the workforce due to informal caring is costly not only to individuals and but also to governments (i.e. lost tax revenue and increased transfer payments)

• Better information on the costs of lost productivity due to informal caregiving for both individuals and the government is needed for setting public health priorities (and labour force policy), and implementing cost-effective health interventions that include some measure of productivity.

• Outcomes can be used to (1) by government, to inform policy and (2) for clinicians or groups such as Carers NSW to advocate for increased resources
Implications

More replacement care

More flexible workplaces

Carer Gateway

ndis

myagedcare

Carers NSW Australia

MACQUARIE University

Sydney, Australia

WORK & CARE

The Necessary Investment

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Thank you!

Further reading


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Model assumptions

Real growth rate of

• 1% per year for personal incomes (based on the long-term growth in average weekly earning)

• 1% per year for income taxes

• 1% per year for pension component of government welfare payments (eg Aged Pension, Carer Payment and Disability Support Payment)

• 0% per year for allowance component of government welfare payments (eg. New Start Allowance) based on Australian Government policy of only increasing allowance in line with consumer price index growth
• Change in socio-demographic structure of the population were captured through static ageing

• Reweighting the dataset to the projected Australian population

• A reweighting algorithm \textit{GREGWT} (SAS macro) from the ABS
  • based on generalised regression method
For socio-demographic and economic changes:
• Projected Australian population and labour force participation in the 2015 Intergenerational Report (IGR) by the Australian Treasury
• Other socio-demographic changes based on APPSIM distribution applied to the 2015 IGR population projection

Projected number of informal carers
## Cost of retiring early due to informal caring – full time – all Chronic Conditions

### Differences in economic outcomes, Australians aged 15-64 years

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total weekly income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between emp FT non carers and NILF due to caring primary carers</td>
<td>936.33</td>
<td>1,136.47</td>
</tr>
<tr>
<td></td>
<td>(897.77; 992.31)</td>
<td>(1,097.34; 1,189.84)</td>
</tr>
<tr>
<td><strong>Total weekly transfer payments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between emp FT non carers and NILF due to caring primary carers</td>
<td>-308.26</td>
<td>-339.77</td>
</tr>
<tr>
<td></td>
<td>(-312.33; -304.24)</td>
<td>(-343.65; -335.62)</td>
</tr>
<tr>
<td><strong>Total weekly tax payments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between emp FT non carers and NILF due to caring primary carers</td>
<td>260.58</td>
<td>311.62</td>
</tr>
<tr>
<td></td>
<td>(247.35; 274.98)</td>
<td>(297.76; 329.23)</td>
</tr>
</tbody>
</table>
## Cost of retiring early due to informal caring – part-time – all chronic conditions

### Differences in economic outcomes, Australians aged 15-64 years

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total weekly income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between emp PT non carers and NILF due to caring primary carers</td>
<td>336.38</td>
<td>418.85</td>
</tr>
<tr>
<td></td>
<td>(310.12; 363.78)</td>
<td>(392.42; 446.37)</td>
</tr>
<tr>
<td><strong>Total weekly transfer payments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between emp PT non carers and NILF due to caring primary carers</td>
<td>-257.3</td>
<td>-288.15</td>
</tr>
<tr>
<td></td>
<td>(-263.91; -250.55)</td>
<td>(-293.93; -282.02)</td>
</tr>
<tr>
<td><strong>Total weekly tax payments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between emp PT non carers and NILF due to caring primary carers</td>
<td>80.43</td>
<td>93.57</td>
</tr>
<tr>
<td></td>
<td>(72.24; 89.33)</td>
<td>(86.23; 101.64)</td>
</tr>
</tbody>
</table>