Impact of chronic health conditions on families across the life-course

COMPASS Colloquium
5 August 2021
Barry Milne
Background

• Chronic conditions (cancer, cardiovascular disease, diabetes, mental health and obesity)
  – Leading cause of premature death and disability
  – High rates among Māori and Pacific populations
  – Impacts to the individual on functioning and quality of life well established
What causes the most deaths?

- Communicable, maternal, neonatal, and nutritional diseases
- Non-communicable diseases
- Injuries

<table>
<thead>
<tr>
<th>Disease</th>
<th>2009 Rank</th>
<th>2019 Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ischemic heart disease</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Stroke</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>COPD</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Alzheimer's disease</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Colorectal cancer</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Lower respiratory infect</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

Global Burden of Disease – New Zealand
http://www.healthdata.org/new-zealand
Figure 30: Age-standardised COPD hospitalisations in adults aged 40 years and over by ethnicity and socioeconomic deprivation quintile, 2015

Figure 33: Estimated percentage of New Zealand’s adult population living with diabetes by ethnicity, average over 2013–2015

Impact on families

- Far less known about the impacts on family
- Focus has tended to be either carers (typically older spouses) or children of depressed mothers, or parents of chronically ill children
Carers

• Carers report greater loneliness/isolation, less exercise, greater alcohol use
  • Canadian General Social survey (Ysseldyk et al., 2019)

• Older carers
  – Experience psychological distress
  – Have adverse health outcomes
  – Have lower relationship quality
  – May have work impacted
    • Schulz et al., 2020, Ann Rev Psychol

• Cancer carers
  – Have worse mental health, physical health and sleep
    • Number of studies by Kelly Shaffer and colleagues
Parental depression

• Parental depression shown to impact
  – Childhood obesity
    • Marco et al., 2020
  – Behaviour problems
    • Seay and Kohl, 2015; Harris & Santos, 2020
  – Depression
    • Weissman et al., 2006; Wickersham et al., 2020
  – Maltreatment
    • Ayers et al., 2019

• Limited evidence for physical health impacts
  • Pierce et al., 2020
Parents of ill children

• Increased
  – anxiety/depression
  – CVD/mortality (congenital abnormalities)
    • Systematic review: Cohn et al., 2020
Impact on families

• Gaps in literature
  – Impacts of parents with chronic conditions on children
  – Education, socioeconomic outcomes
  – Full range of family members
  – Full range of carers
  – Multimorbidity
  – Multiply affected families
  – Multigenerational families
  – Family-level descriptives
  – Positives and resilience
Why is this important?

- Estimates and projections for disease burden likely to be greatly underestimated

“Can also have a profound impact on the person’s family, whānau and friends” (p24)

but no data to quantify this
Why is this important?

• Greater recognition and support for the role of carers
  – Extent of caring itself likely underestimated
    • E.g., partner looking after spouse
    • Older children looking after younger children and grandparents
  – The role of young carers
  – Acceptance that caring may be rewarding as well as (instead of) being a burden
Why is this important?

• If burden is underestimated and involves impacts on family members as well as individuals... then should this be factored in when deciding treatments to fund? [...provocative...]
Basic idea

• Obj 1 (PI: Milne): Determine the influence of chronic disease on the wider family at different life stages, with a focus on four areas: children, households, partners and carers, and older adults.
  – Quantitative investigation using administrative data

• Obj 2 (PI: Dewes): Determine the family, household and community strengths that allow people in the Tokelauan community to thrive despite the challenges of living in families with chronic disease.
  – In depth qualitative study
Chronic Disease on Family

• Barry Milne (PI)
• Data management
  – Lisa Underwood (COMPASS), Andrea Teng (UOW)
• Children and Families
  – Lisa Underwood
• Partners
  – Janeen Baxter, Marin O’Flaherty, Jack Lam, Yanshu Huang (UQ)
• Elders
  – Hamish Jamieson, Ulrich Bergler, Lukas Marek (UC)
Impact of chronic disease on families

- Impact on children
- Impact on partners/carers
- Impact on families
- Impact on households
- Impact of multi-morbidity
Stats NZ’s Integrated Data Infrastructure (IDI) is a large research database containing de-identified microdata about people and households.

The IDI contains person-centred microdata from a range of government agencies, Stats NZ surveys, including the 2013 Census, and non-government organisations.

For more information about data in the IDI, see www.stats.govt.nz/integrated-data/integrated-data-infrastructure

The Longitudinal Business Database (LBD) complements the IDI with microdata about businesses. For more information about data in the LBD, see www.stats.govt.nz/integrated-data/longitudinal-business-database

### Benefits and social services data
- ACC injury claims – from 1994
- Benefits – from 1990
- Children’s Action Plan – from 1996
- Child, Youth, and Family – from 1991
- Early Start Project – from 2016
- Family Start – from 2006
- Student loans and allowances – from 1992
- Working for Families – from 2003
- Youth services – from 2004

### Housing data
- Social housing – from 2000
- Tenancy – from 2000

### Income and work data
- Household economic survey – from 2006
- Household labour force survey – from 2006
- NZ Income Survey – from 2006
- Survey of family, income, and employment – 2002–10
- Tax and income – from 1999

### Justice data
- Court charges – from 1992
- New Zealand crime and Victims Survey – from 2018
- NIA Links – from 2005
- Recorded crime: offenders – from 2005
- Recorded crime: victims – from 2014
- Sentencing and remand – from 1998

### People and communities data
- Auckland City Mission – from 1996
- Disability survey – 2013
- Driver licence and motor vehicle registers
- General Social Survey – 2006–2018
- Longitudinal Immigration Survey of NZ – 2005–09
- Migrant Survey – from 2012
- Te Kupenga – 2013

### Population data
- Census – 2013, 2018
- Births, deaths, and marriages – from 1840
- Border movements – from 1997
- Civil unions – from 2005
- Departure and arrival cards – from 1997
- Visa applications – from 1997

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National Science Challenges
AGING WELL
Kia eke kairangi ki te taikaumātutanga
HEALTHIER LIVES
He Oranga Hauora
National Science Challenges
A BETTER START
Impact of chronic disease on families
Methods

• Define and characterise households (2013 Census)
• Define chronic conditions among household members (2013)
  – Acute Myocardial Infarction
  – Cancer
  – Chronic Obstructive Pulmonary Disease
  – Coronary Heart Disease
  – Diabetes
  – Gout
  – Stroke
  – Traumatic Brain Injury
  – Dementia
  – Mental Health
Basic descriptive questions

1. How many families include a family member with a chronic condition?

2. How many families include a family member with multi-morbid chronic conditions?

3. How many families include more than one family member with a chronic condition?

4. Does 1,2,3 differ by socio-economic status, ethnicity and family structure?
Substantive questions

5. How are health, education and wellbeing outcomes for children impacted by living in a family with chronic disease?

6. How are employment, income, and physical and mental health impacted over time for the partners and carers of chronic condition sufferers?

7. How is the health, mental health, and lives of the parents and elders of chronic condition sufferers impacted over time?

8. How does having a family member with a chronic conditions change families and households over time, in terms of family composition and household resources?
Analyses

• Analyses run on the whole population and stratified by major ethnic groups (European, Māori, Pacific, Asian).
• Subgroup analyses run for Tokelauan ethnic group
• Assess whether some chronic conditions have greater impact than others
• Account for functional impairment of condition
• Try to identify ‘protective’ factors
  – Disease free family members, residential stability
Limitations

• Analysis of administrative data is good for understanding what is going on for populations, but...
  – If we find an effect (e.g., children less likely to stay in education or training), we don’t know WHY it came about
  – An effect in aggregate may mask lots of different things going on for individuals
  – We can (mostly) only focus on negative outcomes; we can’t uncover all the positive impacts of (e.g.) caring for a family member

• Extremely important that we augment our findings with in depth qualitative analyses
Tokelauan families study

• “Intergenerational, integrative & intellectual Pacific properties & pathways for Life (IP4Life)”

• Obj 2 (PI: Dewes): Determine the family, household and community strengths that allow people in the Tokelauan community to thrive despite the challenges of living in families with chronic disease.

• Qualitative investigation in two sites
  – Wellington (53% of Tokelauan population)
  – Auckland (24% of Tokelauan population)
  – Purposive sampling through collaborating service providers
Outcomes and impacts

• Contribute to policy development around support needed for families

• Better capture the wider impact of chronic conditions, for each chronic condition
  – Can contribute to cost estimates and treatment funding decisions

• Raise awareness that what happens to individuals affects families – move away from an individual focus
THANK YOU!

QUESTIONs?