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

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

Hospitalisations per 100,000 people

- Quintile 1 (least deprived)
- Quintile 2
- Quintile 3
- Quintile 4
- Quintile 5 (most deprived)

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

Data in the IDI  March 2021
Impact of chronic disease on families
Methods

• Define and characterise households (2013 Census)
• Define chronic conditions among household members (2013)
Ten Chronic Conditions

• 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
Example analysis

RQ: Does growing up in a family with a chronic disease sufferer impacts on educational attainment?

1. Identify families in 2013 with chronic disease sufferers with children aged 12-16.
2. Assess NCEA2 results 2013-2019 (most children aged 12-16 will have had an opportunity to attain NCEA2 by 2019).
3. Match children by age, sex, ethnicity, deprivation, region to a group of children without a chronic condition in the family.
4. Groups compared to determine whether NCEA2 attainment is more or less likely among children in families with a chronic disease sufferer.
5. If there is an association, we will investigate the impact of (i) chronic disease type and (ii) potential protective factors among children in ‘chronic disease’ families using a ‘moderation’ (interaction) approach.
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
Associated Projects

• Te Kura Mai i Tawhiti
  – Develop conceptual framework and methodology for a life course wellbeing project through the delivery of whanau-based early childhood education (Taranaki)
  – Mihi Ratima, Will Edwards, Gareth Treharne, Aroaro Tamati, Ruakere Hond, Erana Hond Flavell

• E kore au e ngaro
  – Document conceptual framework for a whakapapa-centred approach to intergenerational wellbeing research, based on Ngati Tiipa (Waikato) whakapapa genealogies
  – Tahu Kukutai, Ella Newbold, Vanessa Clark, Heeni Kani
Associated Projects

• Possible implementation pathways, through whanau in Taranaki and Ngati Tiipa

• Advice on Māori data sovereignty issues
  – ‘In house team’ guidance on use of data
  – Given this study is nationwide using SNZ data, should be governed by Mana Orite agreement between SNZ and Data Iwi Leaders group
Tokelauan families study

- Tokelau population has high health needs (#1 most prevalent diabetes population in the world) but seldom the focus of research
- The Tokelau Migrant Study (Prior et al, 1974) ‘one of the most prominent examples of population context epidemiology during the “modern epidemiology” era (Pearce, 2009). Our study will enable historic comparisons.
- Population is small (n=8000), well networked, and less geographically spread than other NZ Pasifika groups
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
Tokelauan families study

• Engage community leaders and family members as ‘co-researchers’ to identify solutions to addressing the impact of chronic diseases within families

• 12 community workshops, 6 focus groups, 15 family interviews
  – Facilitated by Pasifika researchers fluent in Tokelauan
  – Structure determined by ‘co-researchers’
  – Talanoa model – story telling with
    • Ofa/love, Mafana/warmth, Malie/humour, Faka’apa’apa/respect
  – Narrative and thematic analyses
Tokelauan families study

- Ofa Dewes (PI, COMPASS)
- John Fiso (Pacific Health Plus)
- Glenn Doherty (Tongan Health Society)
- Tokelauan Leaders in Auckland and Wellington
- Pasifika research interviewers
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?