

Research into the mental health of young carers

Dr Becca Lacey

Population Health Research Institute
St George's, University of London

- How many young carers are there in the UK?
- What does the evidence say on the mental health of young carers?
- How does mental health change around becoming a young adult carer?
- Where next?

Young caring

Young person aged <18 years who looks after someone because of disability, illness, mental health condition, addiction or problems related to old age



How many young carers are there in the UK?

Great question!

Let's ask adults...

Census England & Wales

1.4% of young people aged 5-17
4.6% of young adults aged 18-24

School Census England

0.5% young people aged 5-18 in schools

Let's ask young people themselves...

BBC Survey 2018

10% young people providing high/v.high levels care
~2 per class

COSMO (2021/22)

13% young people aged 16/17

Understanding Society (2021-2023)

12.3% young people aged 10-17

Problems of identification:

- Massive under-reporting in schools and in the Census
- Language is crucial – many young people don't know what “care” is, and young carers and their families don't identify themselves or their children as carers
- Identification is paramount to supporting young carers & their mental health

What do we know about the mental health of young carers?



“Big Ask” 2022, children aged 6-17

- Young carers were more unhappy than other children – this differences got bigger as they got older (Office of Children’s Commissioner, 2022)

ME-WE project 2022

- 56% of young carers said their mental health had got worse because of their caring role; 30% had thought of self-harming; 12% thought about harming others (incl. who they were caring for)

What is a systematic review?

Comprehensive summary of all evidence on a specific topic

One of the strongest forms of evidence:

- Review is conducted following a series of pre-defined steps that aim to minimise bias and maximise the thoroughness of the review
- Provides a thorough summary of evidence on a topic
- Assesses the quality of existing evidence

Provides a reliable source of evidence for policy and practice

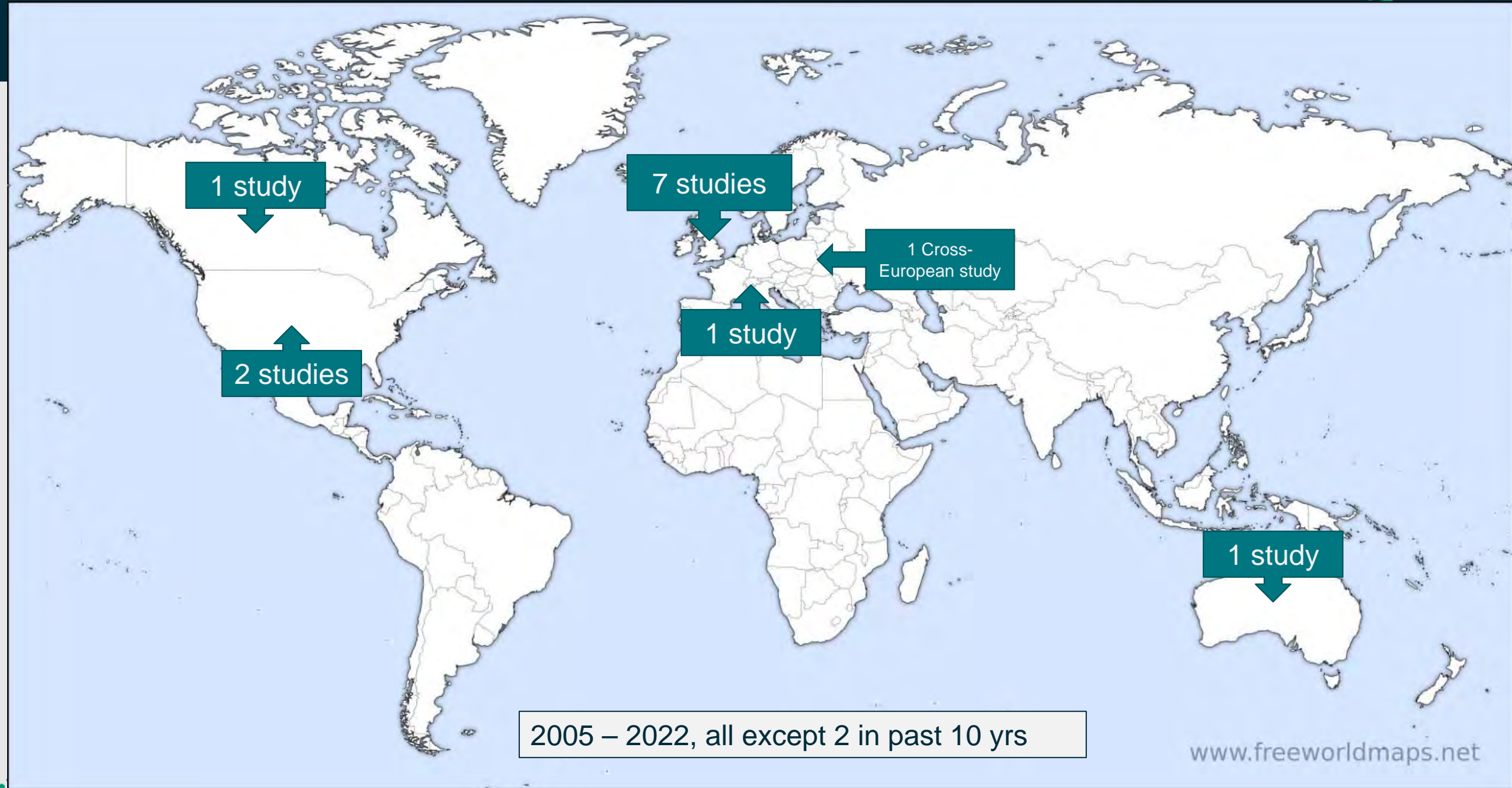
Previous reviews of health of adult carers:

- Mental health (Bom et al, 2019; Del-Pino-Casado et al, 2021; Pinguart & Sorenson, 2003)
- Physical health (Bom et al, 2019; Pinguart & Sorenson, 2003)
- Carers of people with specific conditions (Masefield et al, 2020; Pousada et al, 2013)

No review of the health of young carers

- Cannot assume that the health consequences of caring in childhood or adolescence are the same as in adulthood

- Studies published in English
- Quantitative studies
- Include a comparison group of non-carers
- Defined young carers as those aged <18 years
- Quantify at least one association between young caring and a measure of physical or mental health



- 12 studies were cross-sectional, only one longitudinal
- Samples from 40 – 773,422 people
- 5 studies physical & mental health outcomes, 7 studies only mental health, 1 study only physical health
- Most studies rated as “high quality”
 - E.g. most had representative samples of young people, sufficiently documented their methods, used reliable & validated instruments to capture to health

All except one study found that young carers had poorer mental health, on average, compared to their peers

- More symptoms of anxiety and depression
- Lower self-esteem
- Poorer health-related quality of life
- More antisocial behaviours
- Higher total scores on the Strengths & Difficulties Questionnaire
- More likely to report chronic mental health condition

Little evidence of gender differences

Care intensity was important

Summary of review

- On average, young carers had poorer mental health (and physical health) than their peers, especially those providing the most intense levels of care
- Relatively new area of quantitative research
- We need more longitudinal studies – this relies on decent data
- We need more studies in low and middle-income countries
- Nuance in what care involves e.g. activities, intensity, who, level of support
- Positive outcomes, not just negative

The mental and physical health of young carers: a systematic review



Rebecca E Lacey, Baowen Xue, Anne McMunn



The health of those who care for someone with a health condition or advanced age is poorer, on average, than non-carers. However, the health of young carers (<18 years of age) has been under-researched, especially in quantitative studies. This systematic review aimed to summarise studies assessing the mental and physical health of young carers. 1162 unique studies were screened and 14 associations between being a young carer and health were identified (two studies were treated as a single unit of analysis as they had information from the same sample). Most of the included studies were done in the UK, with the remaining studies done in the USA, Canada, Australia, and Austria. A cross-European study of 21 countries was also included. Five of the included studies investigated both mental and physical health outcomes, seven studies investigated only mental health outcomes, and one study investigated only physical health outcomes of being a young carer. All of the included studies, except one, were cross-sectional in design. Most studies found that young carers had poorer physical and mental health, on average, than their non-caregiving peers. However, the evidence is relatively weak and more quantitative research is needed, particularly research that is longitudinal in design and assesses physical health outcomes.

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Research Department of
Epidemiology and Public
Health, University College
London, London, UK
(R E Lacey PhD, B Xue PhD,
Prof A McMunn PhD)

Correspondence to:
Dr Rebecca E Lacey, Research
Department of Epidemiology
and Public Health, University
College London,
London WC1E 6BT, UK
rebecca.lacey@ucl.ac.uk

Introduction

caregivers providing intense care).⁸ Furthermore, there

Plugging the longitudinal studies gap:

- Eurocare project (2021-2024) young adult carers in Europe
- Nuffield Foundation project (2023-2026) young carers in the UK

Examining how becoming a carer affects mental & physical health

- How soon after becoming a carer is health affected?
- How long does this effect on health last?

How does health change around becoming a carer?

Aim: To investigate the mental and physical health effects of becoming a young adult carer & whether this varies by gender and caregiving intensity

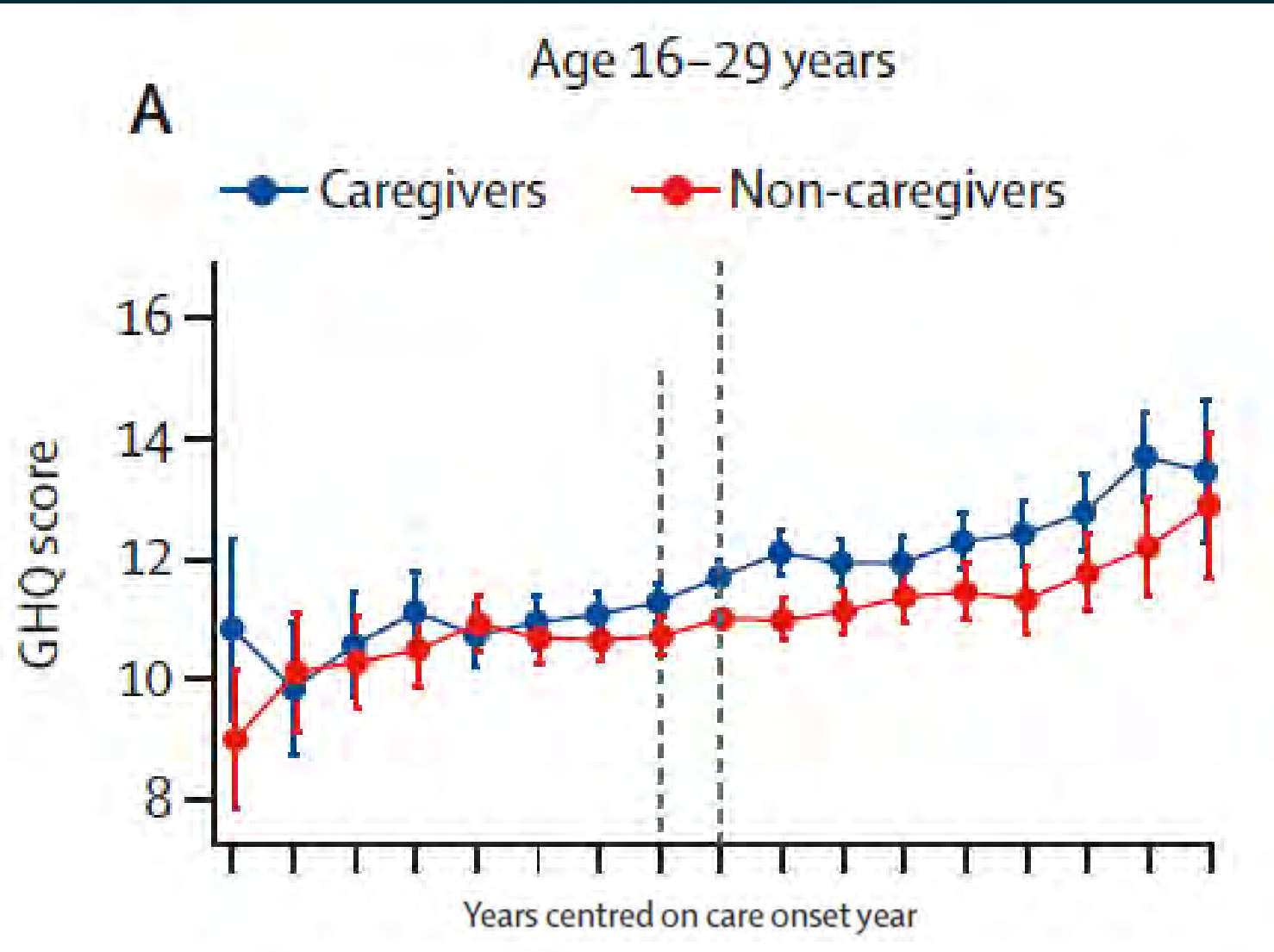
We thought:

- Mental & physical health would deteriorate shortly following becoming a carer
- This would be more pronounced for women and where more intense care was provided

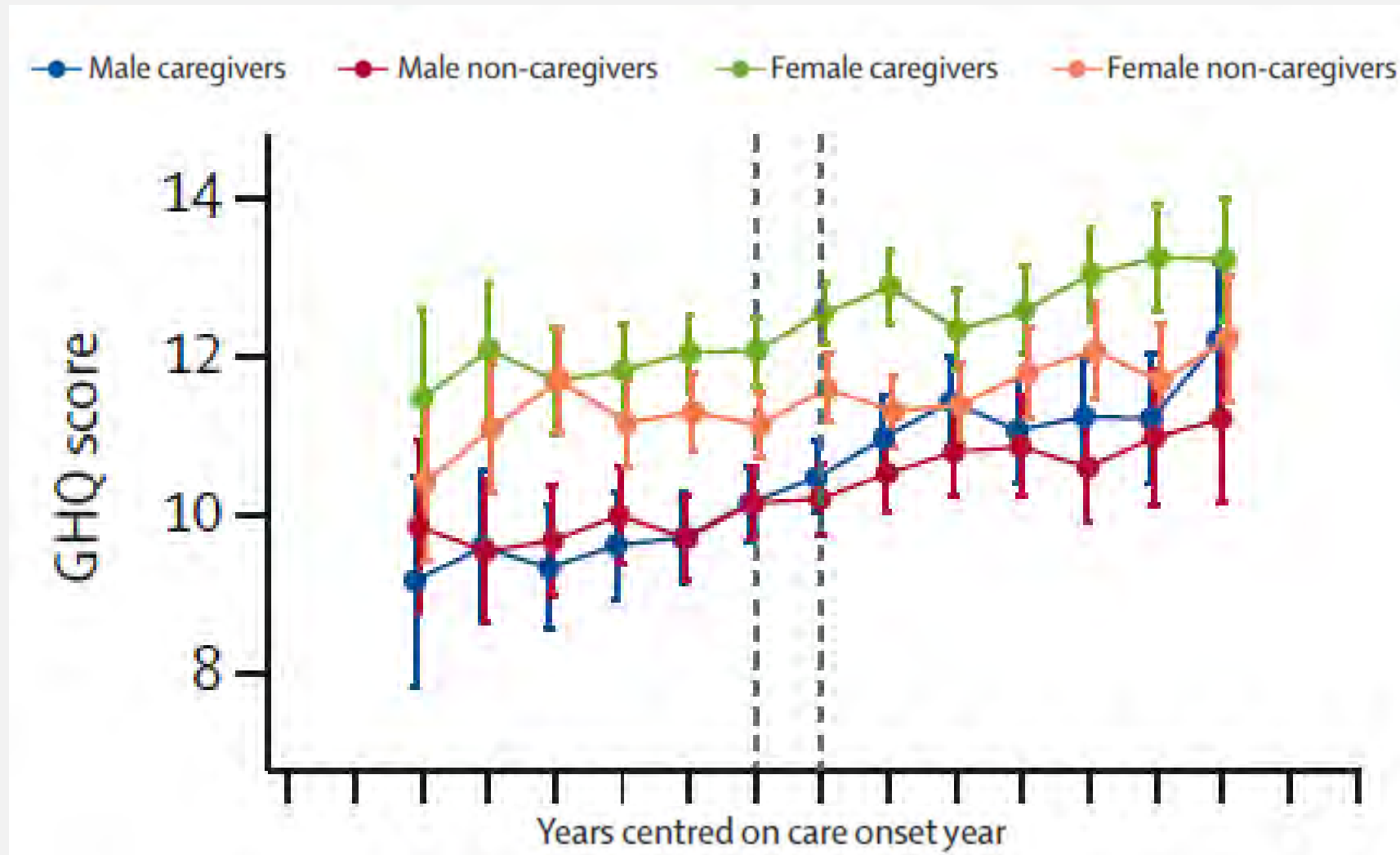
Data: Understanding Society, 10 years of data, people aged 16+
Able to look at health up to 8 years before & after becoming a carer



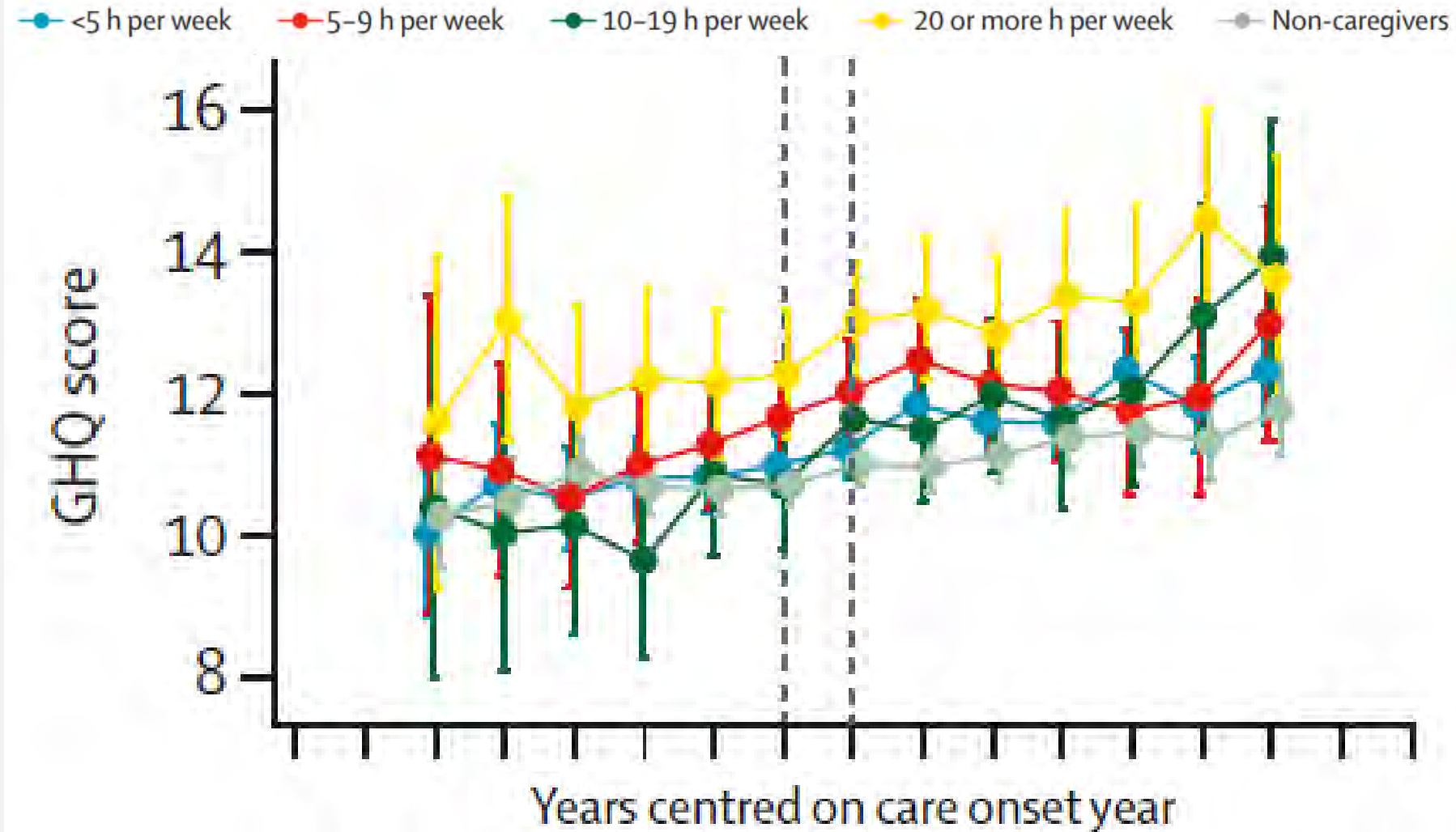
Psychological distress around becoming a carer



Looking at gender differences



Looking at care intensity (hours of care/week)



Becoming a carer is associated with a deterioration of mental health

- Particularly the case for those aged <65 years
- Suggestion that providing more intense care (living with care recipient and/or providing more hours of care)

Didn't see much with physical health change

Young and young adult caring is not uncommon but there is still little societal awareness

Early identification to identify & support carers is key

Healthcare staff play a role here:

- GPs – conversations about care, Read codes for carers
- Hospital discharge teams
- Whole family approaches

Decent data on young carers

Accurate estimates of how many young carers there are

We need more societal awareness of young caring to support identification efforts

Identification in turn is paramount for supporting young carers' mental health

APPG on young & young adult carers



**"BEING A YOUNG CARER,
YOU HAVE TO CHOOSE
BETWEEN YOUR FUTURE
AND THE FUTURE OF THE
PERSON YOU CARE FOR."**

**INQUIRY INTO THE LIFE OPPORTUNITIES OF
YOUNG CARERS AND YOUNG ADULT CARERS**

NOVEMBER 2023

<https://carers.org/downloads/appg-for-young-carers-and-young-adults-carers-reportlr.pdf>

Thank you for listening

Email: rlacey@sgul.ac.uk

Twitter/X: @rebeccalacey

