

# QAR-NET CARE INAUGURAL WORKSHOP

## ‘Bridging Care Gaps: Exploring Impact on Lives and Societies’

Novotel Sheffield Centre, 50 Arundel Gate, Sheffield City Centre, Sheffield S1 2PR

### Monday 3 June

9:00-9:30 **Registration**

9:30-9:40 **Welcome speech**

**Prof Matthew Bennett**, University of Birmingham

9:40-10:30 **Keynote speech**

**IN-CARE (Inequality in Care): How are varying care systems associated with inequalities in care and well-being in later life?**

**Prof Karen Glaser**, Kings College London

10:30-11:00 Coffee and Refreshments

### Health and Wellbeing

11:00-11:25 **Inequalities in wellbeing around becoming a young carer in the UK**

**Dr Rebecca Lacey**, St George's, University of London

11:25-11:50 **Housing improvements and projected costs of social care for older people with depressive symptoms**

**Dr Bo Hu**, London School of Economics and Political Science

11:50-12:15 **The health and wellbeing impact of providing care within the household**

**Becky Pennington**, University of Sheffield

12:15-13:30 Lunch

### Employment and Education

13:30-13:55 **Does the onset of sandwich care make working parents exit from employment or reduce working hours?**

**Dr Baowen Xue**, University College London

13:55-14:20 **The effects of sandwich care on health and employment outcomes in Germany: A longitudinal analysis of the German Socioeconomic Panel study**

**Dr Christian Deindl**, TU Dortmund University

14:20-14:45 **Differences in higher education outcomes by informal carer status**

**Azadeh Abbasi Shavazi**, Australian National University

14:45-15:10 **How social-economic and demographic factors affect individuals' occupational choice**

**Haonan Dong**, University of Sheffield

15:10-15:40 Coffee and Refreshments

### Financial Wellbeing

15:40-16:05 **Understanding the characteristics of unpaid carers living in financial hardship: Risks and inequalities**

**Dr Javiera Cartagena-Farias**, London School of Economics and Political Science

16:05-16:30 **Financial Distress and Psychological Wellbeing of Informal Carers in Managing People with Parkinson's Disease: Evidence from the United Kingdom**

**Dr Smruti Bulsari**, University of Essex

16:30-16:55 **The potential costs and benefits of shortening waiting lists for home care for older people in England**

**Rami Cosulich**, University of Sheffield

19:00 Social Dinner (Page 5)

## Tuesday 4 June

### Unpaid Caregiving

- 9:00-9:25 **Estimating the cost of informal care**  
Dr Maria Petrillo, University of Sheffield
- 9:25-9:50 **Do informal carers identified by different methods have different characteristics and outcomes? A comparison of self-declaration and time diary approaches**  
Dr Sean Urwin, University of Manchester
- 9:50-10:15 **Young carers in the UK: Prevalence, correlates, and insights pre- and post-COVID-19**  
Dr Alejandra Letelier, St George's, University of London

10:15-10:45 Coffee and refreshment

### Unmet Needs

- 10:45-11:10 **Temporal dynamics of unmet needs for long-term care: An age-period-cohort analysis**  
Dr Jingwen Zhang, University of Sheffield
- 11:10-11:35 **How is the quality and suitability of older people's housing related to their care use**  
Dr Nicola Brimblecombe, London School of Economics and Political Science
- 11:35-12:00 **Projection of Unpaid Care Demand Using Cohort Component Method**  
Dr Daniel Valdenegro, University of Oxford

12:00-13:00 Lunch

13:00-14:30 **Collaboration Session**

# Conference Venue & Contact Details

## Driving to Novotel Sheffield Centre

### Novotel Sheffield Address

50 Arundel Gate  
Sheffield  
S1 2PR

### Novotel Sheffield Contact Number

0114 2781 781

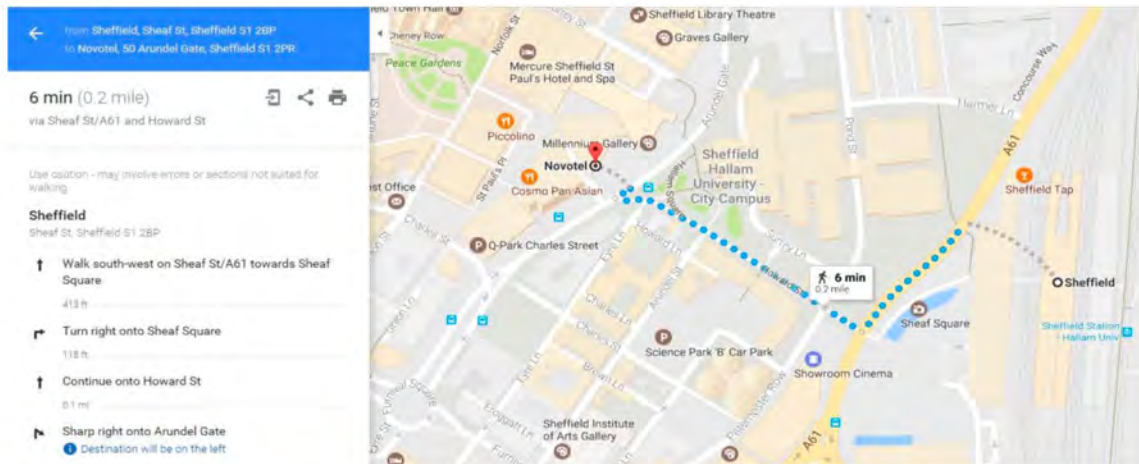
Parking is available at the hotel on a first come, first served basis @ £10.00 for day guests & £15.00 for overnight residents.

Should the Novotel not have any spaces available, we recommend to park at the Q Park on Charles Street where we can provide a discounted validation ticket from reception.

(72 Charles St, Sheffield S1 2NB)



## Directions from Sheffield Train Station to Novotel Sheffield Centre



### Novotel Sheffield Address

50 Arundel Gate  
Sheffield  
S1 2PR

### Novotel Sheffield Contact Number

0114 2781 781

**Time: Sun, 2 Jun 2024 - Tue, 4 Jun 2024 (2 nights)**

**Check-in: from 15:00 Check-out: until 12:00**

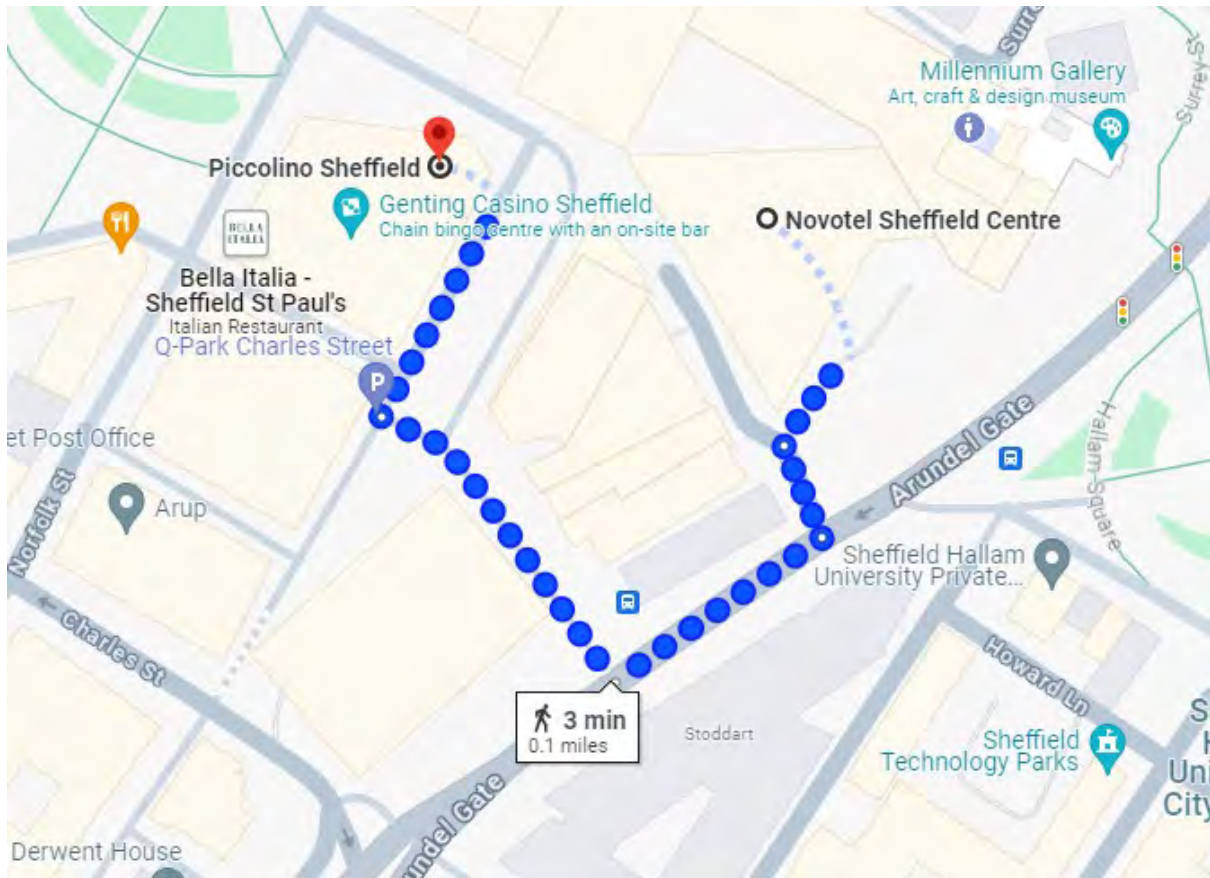
Please contact **Maria Petrillo** (+44 7729346468) or **Jingwen Zhang** (+44 7368805794) if you have any questions.

# Social Dinner

## Piccolino Restaurant

Address: 4 Millennium Square, Sheffield City Centre, Sheffield S1 2JJ

## Direction to Piccolino from Novotel Sheffield



# Conference Abstracts

## Health and Wellbeing

### **Inequalities in wellbeing around becoming a young carer in the UK**

*Dr Rebecca Lacey, St George's, University of London*

*Introduction:* Caring responsibilities are associated with lower levels of wellbeing in young carers. While much of the existing literature relies on cross-sectional designs and focuses on older age groups, this paper adopts a longitudinal approach to investigating how wellbeing changes around becoming a young carer. We also assessed how this might differ for different groups of young carers.

*Objective:* To investigate how wellbeing changes when becoming a young carer and examine how this varies by age, care intensity (weekly hours spent caring), gender, ethnicity, and household income.

*Methods:* This study used data from the UK Household Longitudinal Study, focusing on individuals aged 10-25 from Waves 1 through wave 13 (spanning the years 2009-2023). Wellbeing was measured via self-reported life-satisfaction and self-esteem. Employing Propensity Score Matching, carers were paired with non-carers. Then, linear piecewise growth curve modeling examined wellbeing trajectories pre-, during, and post-caring. The analysis included 4,424 individuals, examining the trajectories of carers versus non-carers, with further stratification by care intensity, age, gender, ethnicity, and household income.

*Results:* Life satisfaction declined when becoming a young carer relative to non-carers. A difference in life satisfaction emerged around three years before reporting becoming a young carer. The change in life satisfaction when becoming a young carer did not vary by age group, gender, or ethnicity. However, young carers who were caring for >10 hours per week and those in the lowest fifth of household income had lower levels of life satisfaction two to three years before reporting becoming a young carer. We saw no differences in self esteem upon becoming a young carer, nor did these differ by age group, gender, ethnicity, care intensity or household income.

*Conclusions:* Life satisfaction, but not self-esteem, declines when becoming a young carer. This was particularly the case for young carers from the most deprived households and those taking up larger care loads. There is evidence that for some young carers a decline in life satisfaction begins prior to reporting being a young carer. This is consistent with caregiver identity theory where carers identify as a carer a while (sometimes years) after having taken up the role. Overall, our findings highlight the importance of early identification and support of young carers to prevent declines in wellbeing. Also these findings support strategies to reduce the amount of care that young people are providing.

## **Housing improvements and projected costs of social care for older people with depressive symptoms**

Dr Bo Hu, London School of Economics and Political Science

Poor housing conditions pose substantial threat to people's mental health and contribute to inequalities in social care needs. However, their economic consequences for the social care sector have not been thoroughly investigated. This study makes projections of social care demand and social care costs for older people with depressive symptoms (aged 65 and over) under different housing intervention scenarios. Drawing on data from the English Longitudinal Study of Ageing (ELSA), we combined a Markov model with a Macrosimulation model to make projections. We project that the costs of unpaid care will rise from £33.6 billion to £59.9 billion, and the costs of formal home care will rise from £4.2 billion to £8.1 billion between 2022 and 2042 in the base case scenario where there are no interventions to improve housing conditions. In a scenario where all housing problems are remedied, the costs of unpaid care and formal home care for older people with depressive symptoms are projected to be £56.4 billion and £7.8 billion, respectively, in 2042. Housing improvements reduces social care demand by delaying and reversing the progression of depressive symptoms, which has the double benefits of elevating personal wellbeing and generating cost savings in social care.

## **The health and wellbeing impact of providing care within the household**

*Becky Pennington, University of Sheffield*

*Research question:* Providing care within the household may lead to worse health and wellbeing. Worse outcomes may be partly related to selection into caring, that is, people who become carers differ from those who do not in characteristics that may lead to poorer health. We aimed to understand which characteristics of within-household caring have an effect on the carer's outcomes and to quantify the causal effect of providing care after controlling for those characteristics that may differ between carers and non-carers.

*Data and research methods:* Using 13 waves of data from Understanding Society (the UK Household Longitudinal Study) we linked up each carer with the person they cared for and followed them over time. We included observations before caring began, during caring, and after caring ended. We examined two outcomes for carers: the Short-Form 6 Dimension (SF-6D) calculated from 7 domains/questions of Short-Form 12 Questionnaire, and General Health Questionnaire (GHQ). SF-6D is a generic measure of health-related quality of life and GHQ measures subjective wellbeing. We included variables to account for volume of care and duration of caring, as well as the health/wellbeing of the person cared for. We also incorporated carer and cared-for demographics and variables related to income and home ownership. We used fixed (and random) effects models to control for within-person unobservable characteristics to understand changes in carer's health and wellbeing over time.

*Preliminary findings:* In our sample, carers had statistically significant lower SF-6D and GHQ compared to when they were not actively providing care, but they also displayed significant

differences in most of the variables that could affect health and wellbeing, so it was essential to adjust for these to disentangle the true causal effect. We consistently found evidence of a statistically significant positive relationship between the health or wellbeing of the carer and the cared-for, with an effect size of around 0.1 for all outcomes and models. Thus, carers of people with worse health and wellbeing have worse health and wellbeing themselves and the carer's health and wellbeing worsens as the health and wellbeing of the person they care for declines. Worse cared-for SF-6D is statistically significantly associated with worse outcomes for carers across all domains, with the coefficient greatest for mental health, feeling downhearted or depressed, and social functioning. We also found a statistically significant negative relationship between duration of care and the carer's health and wellbeing, suggesting that caring has a detrimental impact over a sustained period. Considering the domains of SF-6D, an increased duration of caring was statistically significantly associated with worsening role functioning, physical health, and social functioning. Evidence for the relationship between the volume of care and carer's health or wellbeing was less clear. There was no statistically significant relationship for GHQ. For SF-6D it appeared that people had better outcomes when providing medium-volume care than when providing no care, but that this positive effect did not exist for low- or high-volume care. This positive effect was limited to domains for physical functioning and pain.

## Employment and Education

### **Does the onset of sandwich care make working parents exit from employment or reduce working hours?**

*Dr Baowen Xue, University College London*

*Background:* Increasing life expectancy is leading to an increasing number of older people in need of some form of care and the UK relies on adult children to provide much of this care. The simultaneous provision of care to both children and adults, also known as 'sandwich care', occurs in mid-life, often alongside employment commitments. This may have important implications for labour market outcomes, yet little is known about it from longitudinal studies. This study investigates the impact on labour market outcomes of taking up adult care amongst working parents, as well as whether these associations vary by gender of sandwich carers.

*Data:* This study uses ten waves of the UK Household Longitudinal Study, a large, nationally representative panel study in the United Kingdom. Data were collected annually between 2009-2020. Our samples are working parents of children under age 16. To allow for longitudinal statistical analysis, the included sample all have participated in at least two consecutive waves.

*Methods:* We used the difference-in-differences (DiD) method to test the effect of sandwich caring on changes in labour market outcomes. DiD is a quasi-experimental approach that compares the changes in outcomes over time between the treatment group and the comparison group. Changes in sandwich care include non-sandwich caring (no adult care in two consecutive waves), new sandwich caring (no adult care in one wave & provide adult care



in the next wave), continuing sandwich caring (provide adult care in two consecutive waves), and past sandwich caring (provide adult care in one wave & no adult care in the next wave). Changes in labour market outcomes from one wave to the next wave include continuing working, reducing working hours and exiting the labour market. The comparison group is the non-sandwich caring group. To account for the selection into becoming a sandwich carer, we also include gender, age, partnership status, and number of children in the household as covariates. All covariates are measured at one wave before any employment transitions. We use the above covariates to generate a weighting and include the weighting in the DiD model.

*Results:* More than 80% of the sample are non-sandwich carers and 9% are continuing carers. 3% become a new sandwich carer and there is also 3% become a past sandwich carer. We found that, compared to non-sandwich caring working parents, all three sandwich caring groups, including new sandwich caring, continuing sandwich caring, and past sandwich caring, are more likely to exit from employment rather than continue working. This effect is stronger for working mothers than for working fathers. Interestingly, we found that, among working mothers, continuing sandwich carers are less likely to reduce working hours than non-sandwich carers. This is probably because the continuing sandwich care women are already working part-time before becoming sandwich carers.

*Conclusion:* Becoming a sandwich carer may influence working parents' labour market outcomes. Targeted support is required for the portion of parents who are also providing adult care.

## **The effects of sandwich care on health and employment outcomes in Germany: A longitudinal analysis of the German Socioeconomic Panel study**

*Dr Christian Deindl, TU Dortmund University*

The provision of informal care has received a lot of attention during the past few decades, as care needs increased, but also the re-structuring of welfare arrangements put more emphasis on individual responsibilities and incentives to tackle social questions on a more individualized and market-based basis. Additionally, increases in life expectancies lead to a growing population of adults who simultaneously still have parents that are alive and have children they have to care for, for a longer time in their life. In case of occurring parental care needs, these adults may see themselves confronted with the task to juggle providing informal care to their parents and care for their child at the same time. These carers are typically called "sandwich" or "multigenerational carers". Sandwich care comes with its very own unique types of challenges in combining childcare, informal care and other obligations. The combination of both types of care may amplify negative effects of both types of care, e.g. by increasing feelings of being stressed and running out of time to accomplish all responsibilities on time or even lead to different effects than just a single time of care, e.g. by turning the time spent with one's child into a more stressful situation because of the other existing care demands.

The aim of this paper is to analyse the associations between childcare, informal care and the combination of child and informal care (sandwich care) and the carer's employment status (working hours, income), their health and wellbeing using a large representative German longitudinal dataset that includes carers from a wide array of age groups.

Using data from the 2001-2018 waves from the German Socio Economic Panel (GSOEP), we investigated the association between childcare, informal care, and sandwich care on labour earnings, work-time, self-rated health and life satisfaction of caregivers aged 17-64 using (lagged) fixed-effect models. Our results showed that the provision of sandwich care, as well as an increase in care intensity is associated with a reduction in labour earnings, working hours and satisfaction with life. Additionally, we were able to find that the effects for labour earnings and working hours also persist for at least one wave after the provision of care. Analysing our data stratified by sex revealed that only women show significant decreases in their labour earnings and satisfaction with life if providing sandwich care.

The provision and intensity of sandwich caring can have a significant negative impact on the carers' life and this impact is still structured by gendered differences. The results of comparing different types of care suggest that combination of different types of care that is inherent in sandwich care comes with its own unique set of challenges and stressors for the carers. Due to this, a greater emphasis on sandwich carers as their own intervention group, with specific needs and challenges, may be advisable.

### **Differences in higher education outcomes by informal carer status**

Azadeh Abbasi Shavazi, Australian National University

Informal caregiving has many societal benefits but is associated with health and wellbeing costs to carers. Research on the higher educational outcomes of carers is limited and carers aren't considered in most education equity frameworks. With 2.65 million informal carers in Australia and a quarter under the age of 44, identifying opportunities to support their education decision is crucial. Our paper utilises linked administrative data to analyse differences in higher education outcomes by carer status.

Informal carers in our study are those who provide unpaid assistance to others living with a disability, long-term health condition, mental ill health, or age-related frailty. This research marks the first comprehensive analysis of higher education outcomes by carer status by investigating completion likelihood, time to completion, likelihood of suspension, and differences in study load between informal carers and non-carers in Australia, conditional on observed characteristics.

We focus on multivariate longitudinal analysis to estimate the outcomes by carer status, while adjusting for demographic and socioeconomic factors. The cohort of study are individuals actively engaged in higher education as of August 2016, with carer status identified from the 2016 Census. Individuals are followed to 2020.

We test the hypothesis that informal carers have lower chances of higher education engagement and completion, lower study loads, take longer to complete and more likely to suspend study than non-carers. Our theoretical model explains this as being due to the time burden and resource constraints faced by caregivers.

We utilise a unique linked and longitudinal person-level administrative data accessed through the Person-Level Integrated Data Asset of Australia (PLIDA). The datasets provided through PLIDA for this study include:

- Australian Census of Population and Housing to identify informal carer status and other factors.
- Higher Education Administrative data for higher education enrolment, study load and completion information.
- Other datasets relating to taxation and social security to adjust for factors like employment status, income and welfare receipt.

Other survey data such as the Household, Labour, and Income Dynamics in Australia (HILDA), and the Survey of Disability, Ageing and Carers (SDAC), aggregated Census data or the Australian Census Longitudinal Dataset (ACLID) do not have the depth of information on education outcomes and sufficient count numbers to meaningfully respond to the proposed longitudinal research questions.

Findings from this research provide foundational insights into the educational outcomes of informal carers in Australia. These insights can inform policymaking aimed at promoting equitable access to education and supporting the wellbeing of carers. Additionally, the study lays the groundwork for future longitudinal investigations into the needs and experiences of informal carers, facilitating tailored interventions and support services.

Preliminary findings from this research are being cleared by the Australian Bureau of Statistics and data custodians are being informed.

### **How social-economic and demographic factors affect individuals' occupational choice?**

Haonan Dong, University of Sheffield

Abstract:

The UK adult social care has been facing a long-term crisis for several decades, with labour shortage being the most prominent challenge. Annual reports for Skills for Care reveal it is that social care roles are less attractive due to low wage rates, high pressure and stressful environment, low satisfaction and lack of opportunities for promotion. Existing literature that has analysed the social care employee data (the ASC-WDS) confirmed these factors. There is however limited evidence relating to what observable characteristics (both demographic and socioeconomic) influence an individuals' propensity to engage with the care sector. Recent statistics show that despite a temporary decrease in the shortage of care workers during the lockdowns to approximately 0.11 million between 2020 to 2021, the gap has rebounded to 0.165 million in 2022, and the proportion of this gap relative to the overall predicted demand

has also increased; this potentially suggests that, without appropriate policy incentives or support, the recruitment and staff retention challenges are likely to persist and could potentially worsen.

This study draws on the UK Household Longitudinal Survey (the UKHLS) which contains individual and household-level data relating to those in and out of the care sector from 2011 to 2022 to assess how social-economic and demographic factors affect individuals' occupational choice, that is, whether individuals enter the care sector or quit. To approximate unbiased coefficient estimates, various econometrics methods are employed to address the potential issues of omitted variable bias, endogenous sample selection, and other sources of endogeneity. Furthermore, we also extend the existing literature by employing dynamic models to account for state dependence. Additionally, to explore heterogeneity across different groups of society, subsample regressions are implemented according to various criterion to enable comparisons between groups and assessments of the differential effects.

The results of the dynamic model indicate that household income level, childcare responsibilities and gender are the most significant and influential determinants in care sector engagement. Marital and health status also seem relevant, being significant in the aggregate model and some subgroup models. Further, state dependence is also found to be a crucial factor, which is consistent with our prior expectations. The unbalanced model accounting for sample selection generally provides similar conclusions in terms of significance levels and coefficient signs. Some of these factors are also found to be significant determinants of respondents' entry and exit decisions, with, e.g., income level increasing the likelihood of job retention, etc. Given that our analysis is based on a more representative sample size, these empirical findings can enable a more precise assessment of how improvements in individual social economic-status and endowments can affect labour market decisions, and provide policy-relevant guidance, such as evaluating and predicting the labour force shifts across care and other sectors given any exogenous shocks. As social care is becoming a growing element of modern life, we expect these findings to be informative for policymakers such that the most vulnerable are supported in the wake of social care marketization and balancing profitability and efficiency.

## Financial Wellbeing

### **Understanding the characteristics of unpaid carers living in financial hardship: Risks and inequalities**

*Dr Javiera Cartagena-Farias, London School of Economics and Political Science*

*Background:* Despite the potential difficulties faced by carers, there is not much research on the factors associated with being an unpaid carer living in poverty, and of any potential risk factors associated with it. The scarce quantitative evidence available, mostly relies on descriptive analysis based on cross-sectional data, which makes it difficult to understand patterns over time and identify solutions. In addition, previous analysis has understood

unpaid carers as a homogenous group, without exploring characteristics that may exacerbate the challenges they face.

*Aims:* This study aims to: i) describe the latest trends in unpaid carer poverty, deprivation, and related difficulties such as their ability to keep up with bills, ii) identify the risk factors of unpaid carers associated with living in financial hardship, and iii) investigate whether the latter change across subgroups (by gender, ethnicity, age group, and intensity of care).

*Data & Methods:* We make use of several waves of the United Kingdom Household Longitudinal Study to quantitatively investigate associations between providing care and poverty levels as measured by low-income, financial distress, and perceived material deprivation. Our analysis includes the estimation of the proportion of carers living in poverty and in deep poverty over time, but we also identify the risk factors associated with being poor. For the latter, we estimate a Logit Random Effect (RE) model. We performed a similar analysis to address factors associated with material deprivation and financial distress. In order to investigate whether certain carers face exacerbated inequalities, we have explored intersectionality effects running the RE models mentioned above for different sub-samples. We focused on four main characteristics: gender, ethnicity, age, and intensity of care.

*Preliminary findings:* Findings show that unpaid carers are more likely to face poverty than non-carers, and this gap has become wider over time. Older age seems to be a protective characteristic associated with a lower likelihood of poverty among unpaid carers. Those carers providing ten or more hours of care are more likely to be poor and to be behind household bills. Nevertheless, they are less likely to be in deep poverty if already poor. The latter findings shed light on the role of welfare support available to carers. The policy implications of this research are multiple, from recognition of the many, sometimes hidden, challenges faced by unpaid carers to providing better income related safety nets for those providing care.

## **Financial Distress and Psychological Wellbeing of Informal Carers in Managing People with Parkinson's Disease: Evidence from the United Kingdom**

*Dr Smruti Bulsari, University of Essex*

*Background:* Parkinson's Disease (PD) is a long-term condition, which is more common among males and people aged 65 years or more. People with Parkinson (PwP) tend to lose motor functions and find themselves in more fatigue and pain, sometimes leading to anxiety, distress and in extreme cases, even depression. So far, there is no cure for PD and they need support from family members, healthcare professionals and carers, as the disease progresses. A large proportion of carers for PwP are informal (spouses and family members). Progression of PD can result in loss of employment, reduced work hours or premature retirement, for both PwP and their informal carers. This poses a huge financial burden as income reduces on one hand, and expenses increase on the other. There is a lack of evidence on the societal costs of PD, and this study tries to fill that gap.

*Objectives:* To examine the impact of financial burden of treatment and care on (1) psychological wellbeing, and (2) quality of life of PwP and their carers in the UK.

*Methods:* A mix of online and postal, cross-sectional survey was administered, which received responses from 853 respondents (consisting of 776 PwPs and 546 caregivers). The survey sought data on management of the socioeconomic, health and living conditions of PwP and their carers. Net effect of financial distress (cost of healthcare use, non-health expenditure, societal costs and other direct/indirect cost components) on quality-adjusted life years measured using EuroQoL 5 dimensions instrument (QALYs and visual analogue scale-VAS), and wellbeing score of PwP and their primary carers are estimated using multiple linear regression models.

*Results:* Financial burden of treatment increase whereas quality of life and wellbeing of PwP decrease with progression of PD. Similar association but of a milder magnitude is observed on quality of life of their primary carers. A strong negative association is found between quality of life of PwP and their carers, with financial burden, while holding for demographic and socioeconomic factors, and for disease progression and treatment. Financial distress is more pronounced among PwP having annual income below £20,000. This survey is largely biased towards white people however a booster sample of ethnic minorities was included representing 5 per cent of PwPs. It is observed that the impact of financial distress could be more pronounced on PwP and caregivers from ethnic minorities.

*Conclusion and Policy Implications:* Cost of care cuts both ways, depleted income from reduced/lost employment as well as increased expenses on healthcare. This results into a considerable financial distress and deterioration in quality of life and wellbeing of both PwP and their carers. Most caregivers are spouses of PwPs, thus their physical and psychological health and wellbeing is found to deteriorate with the progression of PD due to increased burden of care on them. Therefore, informal / family carers should get support from the local government in the form of respite care. This can help revitalise their energy and psychological wellbeing. Financial distress indicators need to be explored further by socioeconomic status.

## **The potential costs and benefits of shortening waiting lists for home care for older people in England**

*Rami Cosulich, University of Sheffield*

*Introduction:* The Association of Directors of Adult Social Services reported that at the end of August 2022 there were 245,821 people awaiting a first assessment of their care and support needs in England. One in three had been waiting for more than six months. This study aimed to assess the potential costs and benefits of shortening waiting lists for home care by six months among older people in England who are eligible for full funding of their home care by the local authority (LA).

*Methods:* Economic modelling was done using a decision tree connected to a Markov cohort model. In the model, people were classified into care states defined by whether they had no care, informal care, LA-funded home care, or both, and by whether their care needs were met or unmet. A proportion of people on the waiting list for LA-funded home care had met needs thanks to informal care. Once LA-funded home care started, the probability of met care needs

increased on average, but some people still had unmet need. A lifetime horizon was used. The model parameters were taken from the published literature on the consequences of unmet need and on the outcomes associated with home care or were estimated analysing data from the English Longitudinal Study of Ageing.

The main outcomes were, in relation to people with care needs: the number of life years, the number of life years adjusted by social care-related quality of life (SCRQoL), public sector (NHS & personal social services) costs, and privately funded costs. In relation to informal carers, only earnings were included. The base case analysis was a probabilistic sensitivity analysis with 2,000 iterations.

*Results:* The base case analysis showed that shortening waiting lists for home care by six months would lead to an increase in life years and life years adjusted by SCRQoL. Moreover, it would result in an increase in informal carers' earnings, as well as in a reduction in NHS and private costs. However, it would also lead to increased personal social services costs and public sector costs. The lowest incremental public sector cost per additional life year would be in the subgroup with no informal care.

*Discussion:* This study has added to the limited previous economic modelling work relating to unmet social care need within the English context. It has also produced the first economic model that focuses on home care provision in England considering a variety of outcomes, although limitations in the available evidence affected the choice of parameters. While the current work modelled home care as delivered in current practice, further work should assess how results may change if home care was better at meeting needs.

## Unpaid Caregiving

### Estimating the cost of informal care

*Dr Maria Petrillo, University of Sheffield*

Informal carers provide the majority of support for people living with long-term illness, disability, or challenges related to older age across Long Term Care systems worldwide. Carers are the lifeline to the most vulnerable within society, yet the care they provide often comes at a cost to their own finances, health and relationships. Estimating the impact of caregiving is central to understandings of inequalities and policy and practice responses to address them. It is also methodologically challenging. This paper breaks new ground by providing the first robust causal estimates of the impact of caregiving on income using novel individual synthetic control methods on nationally representative data. We introduce a new, robust and computationally efficient approach to the individual level Synthetic Control toolbox to do so. Necessary due to violations of parallel trends assumptions inherently necessary in difference-in-difference based estimators, our approach – which is tangentially related to the recently proposed synthetic difference-in-differences – is able to account for unit-level heterogeneity and estimate post-treatment trajectories over time. Leveraging data from the UK Household Longitudinal Study, our baseline estimates identify an income gap of up to 31% between the highest-intensity informal caregivers and their synthetic counterparts. We also show how

these results vary over intersectional characteristics, with the penalty generally being higher for women than men, and for those of a specific type of ethnicity and age. We then show the robustness of our results by differentially filtering data based on length of contiguous sequences and through the undertaking of various placebo tests.

## **Do informal carers identified by different methods have different characteristics and outcomes? A comparison of self-declaration and time diary approaches**

*Dr Sean Urwin, University of Manchester*

*Introduction:* Informal caregiving is widespread, but there is concern that studies do not identify all caregiving that is taking place. This may bias estimates of caregiving effects and lead to ineffective support for caregivers. There is little evidence on whether the method of carer identification uncovers different carers and whether these methods result in different conclusions on caregiving consequences. We investigate whether a time diary compared to a self-declaration method: (i) identifies more and different carers and (ii) alters estimated caregiving impacts.

*Data:* We use the Innovation Panel component of the UK Household Longitudinal Study, which is an experimental set of questions asked to a representative sample of individuals. In wave seven, there are two means of identifying informal carers. First through a time diary where respondents record all activities done in two 24-hour periods. Second, through more commonly used self-declaration questions.

*Methods:* We compare the characteristics of carers identified by a time diary and from self-declaration using linear OLS regression. Using a doubly robust approach of entropy balancing alongside regression adjustment, we assess whether the association of caregiving with mental health, as measured by the GHQ score, changes depending upon the identification method.

*Results:* Out of a sample of 1055 individuals, we identify 261 carers by at least one method. 16% of these 261 carers are only identified through the time diary, and so would be missed if identification was based on self-declaration alone. Time diary-identified carers are more likely to have low household income and be from ethnic minorities. They have a 1.35 ( $p < 0.01$ ) higher GHQ-12 score (measured on a scale 0 to 36 scale where 36 represents the lowest mental wellbeing) than non-carers which is larger than the equivalent coefficient for self-declared carers at 0.51 ( $p > 0.1$ ). The time diary-identified carer gap is large and similar to the difference in GHQ-12 score between those in the lowest relative to the highest household income quintile.

*Implications:* Associations of informal care with health and wellbeing are under-estimated when we only identify carers with self-declaration. Activity-based methods may identify carers earlier and therefore help provide more timely support to carers who may face a greater unmet need for support. Future survey design and the assessment of the scale of caregiving should consider the degree to which caregiving is under-reported. Policies that attempt to aid informal carers should consider that the consequences of caregiving on mental health may be greater than currently understood.



## **Young carers in the UK: Prevalence, correlates, and insights pre- and post-COVID-19**

*Dr Alejandra Letelier, St George's, University of London*

*Background:* Despite increasing awareness of young carers in recent years, there remains a significant gap in our understanding of both the prevalence and the characteristics of young carers. This gap is particularly pronounced in the context of the COVID-19 pandemic, an unprecedented event that has reshaped various social and familial dynamics, including the roles and responsibilities of young carers. This situation underscores the urgent need for up-to-date data on young carers to ensure they receive the necessary support.

*Objective:* To understand the prevalence and characteristics of young carers age 16 to 18 years old living in the UK, pre- and post-COVID-19.

*Methods:* This research utilised data from three UK longitudinal surveys: UK Household Longitudinal Study (UKHLS), The Covid Social Mobility and Opportunities (COSMO), and the Millennium Cohort Study (MCS). We focused on adolescents aged 16-18 and examined two pre-Covid (UKHLS and MCS) and two post-Covid (UKHLS and COSMO) samples. First, the prevalence of young carers in each survey sample was estimated. Subsequently, bivariate logistic regression analyses tested the social and demographic characteristics of young carers pre and post covid. Lastly, the study described the caring characteristics for all young carers, stratified by gender.

*Results:* The prevalence of young carers aged 16-18 increased in the UK from 8.0% pre-COVID to 9.8-11.9% since Covid, with no significant gender differences. Young carers were more commonly found in single-parent households and socioeconomically disadvantaged households, with a higher prevalence of young carers in homes where parents were out of paid employment or held lower educational qualifications. Young carers were also more likely to reside in deprived areas. Most young carers engaged in low-intensity caring, but post-COVID, there was an increase in high-intensity caring. The primary recipients of care were parents, followed by grandparents and siblings, with no change in the care recipient type since COVID.

*Conclusion:* This study shows an increase in the prevalence of young carers, particularly those providing high intensity care, since the onset of the Covid pandemic. Further, young carers are more likely to come from socioeconomically deprived households and areas. Our study highlights the need for targeted support and policies that consider the diverse backgrounds and challenges faced by young carers.

## **Unmet Needs**

### **Temporal dynamics of unmet needs for long-term care: An age-period-cohort analysis**

*Dr Jingwen Zhang, University of Sheffield*

The rapid demographic changes, combined with heavy reliance on informal care, pose significant challenges to meeting long-term care (LTC) needs in China. Understanding change in unmet LTC needs across different times and places can inform future planning of the LTC system and care resource allocation by identifying emerging care needs and evolving gaps in services in different regions. However, research has yet to comprehensively appraise how and to what extent the unmet need has changed during the past two decades. Drawing on data from 6,030 urban and 5,070 rural residents in the Chinese Longitudinal Health Longevity Survey (CLHLS), 2005-2017/18, this study investigates the variations in unmet LTC needs across different age groups, periods and birth cohorts among Chinese older adults and their place-based rural-urban differences. We applied the age-period-cohort interaction (APC-I) model to disentangle the three temporal processes. The study found that, overall, rural older adults experienced a higher risk of unmet needs for LTC, yet the age, period and cohort effects on unmet needs among rural older people differed from their urban counterparts. Although 'younger' older adults (aged below 85) had fewer care needs than older adults, they had a higher risk of experiencing unmet needs. The variation in the age effects was larger among rural older adults. The risk of having unmet needs did not change significantly over the 12 years. The unmet needs for LTC were more pronounced among more recent cohorts than previous generations, especially in urban areas. The findings contribute to the debate in social gerontology regarding the changing patterns in unmet needs for LTC. They also provide crucial policy insights, underscoring the necessity for targeted interventions to address the care needs of 'younger' older adults. The escalating care gap among recent cohorts emphasises the need for increased investment in the formal LTC system.

### **How is the quality and suitability of older people's housing related to their care use?**

*Dr Nicola Brimblecombe, London School of Economics and Political Science*

Recent policy in England states that housing is a key part of reducing and managing care needs and improving people's lives. Research on the topic is scant, particularly for non-purpose built housing where the vast majority of older people live. However, our research shows that, as with health, poor quality, unsuitable housing appears to be a key social determinant of inequalities in care needs. It is associated with younger age of onset and higher level of care need in people aged 65 and older. Poor quality housing is itself unequally distributed exacerbating this inequality. One of the possible impacts of higher care needs is more formal and unpaid care and thus higher costs for individuals and societies if those services are received; greater unmet need if they are not. We sought to understand the role of housing in this relationship. We used mixed methods to explore this and argue that one method alone would not have uncovered the full picture. Methods comprised secondary analysis of quantitative data from the four most recent waves of the English Longitudinal Study of Ageing covering the period 2012/2013 to 2018/2019 (N=8,000+). We used structural equation modelling to explore the direct effects of poor quality housing on care use and the indirect effects via changes in care need. We also carried out semi-structured in-depth interviews with 72 people aged 65 and older with care needs and/or their unpaid carers living in five localities in England and analysed them thematically. Quantitative and qualitative analysis took place

iteratively. We found that poor quality or unsuitable housing can affect use of formal and/or unpaid care in two ways. First through increasing or precipitating care needs thus necessitating (potentially avoidable) increased care use. Second through being a barrier to receiving care resulting in unmet need needs. Both processes sometimes occurred at the same time. Inequalities in care need and in housing quality compounded disadvantage for older people with care needs living in poor quality housing.

### **Projection of Unpaid Care Demand Using Cohort Component Method**

*Dr Daniel Valdenegro, University of Oxford*

This study examines the future demand for unpaid care using the cohort component method, a demographic tool traditionally employed for population projections. The increasing aging population and shifts in family structures in the UK necessitate an in-depth analysis of unpaid care, a crucial component of social and economic systems. By incorporating age-specific fertility, mortality, and migration rates, the cohort component method enables detailed projections of population dynamics over time. This approach allows for the estimation of the future availability and need for unpaid caregivers within different cohorts. Understanding these projections is essential for developing sustainable care policies and support systems. This research contributes to the literature by offering a robust methodological framework for projecting unpaid care demand, facilitating better preparedness and resource allocation to address future caregiving needs. The study underscores the importance of integrating demographic projections with social care planning to ensure the well-being of dependent populations and the sustainability of caregiving systems.