

### Knowledge Exchange Seminar Series (KESS)

...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland



### The Health and Mental Health of Informal Caregivers in Rural and Urban Northern Ireland

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# **Outline:**

- 1. Introduction
- 2. Research Questions
- 3. Literature & Previous Findings

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- 4. Data and Methods
- 5. Findings
- 6. Summary
- 7. Conclusion





# **1. Introduction**

Informal (family-) caregiving plays an increasingly important role in today's ageing societies.

Caregiving is known to have implications for the caregiver's wellbeing, health and mental health.

Knowledge of factors influencing caregivers health and mental health is important to be able to shape and define policies supporting carers in communities.



# **2. Research Questions**

### **Relationships with health and mental health:**

Under what circumstances is informal caregiving in Northern Ireland related to self-reported ill-health and ill mental health?

How is informal caregiving related to the likelihood of individuals of being prescribed anxiolytics and antidepressants?

How relevant are area-deprivation and proximity to services (NISRA 2010)?





# 3. Literature & Previous Findings

There is a substantial body of literature on caregiver wellbeing, health and mental health.

### Main findings in the literature:

- Informal caregiving is often associated with experiences of burden and strain (Morimoto, Schreiner, and Asano 2003)
- This can lead to ill-health and ill mental health, particularly anxiety and depression (Coope et al. 1995; Molyneux et al. 2008; Falloon, Graham-Hole, and Woodroffe 2009)





### Factors found to influence the carer's health and mental health:

- Gender and age
- The number of hours spent caring & of persons cared-for
- Socio-economics: employment status, income
- The intensity of care needed by the cared-for
- The health condition of the cared-for (e.g. dementia, stroke, mental health cond. Etc) (Allegri et al. 2006; Morimoto, Schreiner, and Asano 2003)
- Relationship to the cared-for (spouse, parent in-law...)
- Support (family and friends)
- Policy context (support) (Chambers, Ryan, and Connor 2001)





# 3. Literature & Previous Findings

Informal Caregiving can have both beneficial (Schulz and Sherwood 2008; Beach et al. 2000; O'Reilly et al. 2008) and adverse effects on the carer's health and mental health (Allegri et al. 2006; Morimoto, Schreiner, and Asano 2003) :

-> A majority of studies find that caregiving is related to ill mental health ('strain and burden')

-> However, caregiving can elevate the carer's confidence and provide a feeling of "being needed", "doing something important"

-> Thus, cargiving was found in some studies to be related to better health and mental health.

-> It depends on individual circumstances and on context (e.g. deprivation, access to support and services)



# 4. Data & Methods

### Three data-sources complementing each other:

The Northern Ireland Longitudinal Study (NILS, 2001, 2011): Representative of the population of Northern Ireland N = c. 500,000 (c. 28%) Census- 2001 & 2011-link Variables on self-reported health and mental health Informal caregiving in 2001 and 2011	<ul> <li>The Northern Ireland Health Survey (HSNI, 2010-11):</li> <li>Representative simple random sample</li> <li>Various items on health and two item-batteries on mental health</li> <li>Several questions on care-giving</li> <li>Attitudes and evaluations from the carers' perspective</li> </ul>	
Business Service Organisation (BSO) drug prescription data: Information on drug-prescriptions from GP practices linked to the NILS (anxiolytics, antidepressants)		

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## **Key Variables: NILS**

-> General Health: Census-2001 and 2011-Question "How is your health in general?" (1=very good – 5=very bad)

-> Mental Health: Census-2011- Question "Do you have any of the following conditions which have lasted, or are expected to last at least 12 months? - An emotional, psychological or mental health condition (such as depression or schizophrenia)"

### **BSO Prescription Data, linked to the NILS:**

- Respondent has been prescribed Anxiolytics
- Respondent has been prescribed Antidepressants





# **Key Variables: HSNI**

### **Experiences of Stress and Strain:**

- "How much worry or stress you have had in past 12 months?" (no worry/stress – just a little - quite a lot – a great deal)
- "Have you recently felt under constant strain?" (not at all no more than usual rather more than usual –much more than usual)

#### **Mental Health:**

-> General Health Questionnaire GHQ-12-Score – a validated score of 12 survey questions (Goldberg et al. 1997; Makowska et al. 2002):

**Have you recently...?:** 1 - been able to concentrate on whatever you are doing? 2- lost much sleep over worry? 3 - felt that you are playing a useful part in things? 4 - felt capable of making decisions about things? 5 - felt under constant strain? 6 - felt you couldn't overcome your difficulties? 7 - been able to enjoy your normal day-to-day activities? 8 - been able to face up to your problems? 9 - been feeling unhappy and depressed? 10 - been losing confidence in yourself? 11 - been thinking of yourself as a worthless person? 12 - been feeling reasonably happy, all things considered?



# 5. Findings

	NILS 2011	HSNI 2010-11
Informal Carers	15%	14%
Carers: Hours spent caring	1-19 hours: 56.7% 20-49 hours: 16.1% 50+ hours: 27.2%	1 -19 hours: 59.4% 20-49 hours: 25% 50+hours: 15.6%
Household composition: Carer lives in	Lone carers:58%Two carer-houshold:32%3 or more carer-houshold:10%	n.a.
Gender	Female: 69.7%	Female: 72.7%
Age	16-24: 7.3%, 25-34: 10%, 35-44: 18.6%, 45-54: 27.9%, 55-64: 19.7%, 65-74: 10.6%, 75-84: 4.9%, 85+: 1%	16-24: 10.5%, 25-34: 11.3%, 35-44: 18.2%, 45-54: 26%, 55-64: 17.1%, 65-74: 11%, 75-84: 5.1%, 85+: 0.5%
Ν	333,039 (43,748 carers)	4,085 (616 carers)









# **General Health: in the HSNI**

DV: Self-reported ill- Health	β	S.E.
Carer		•
Hours spent caring: <10	-0.112	0.069
Hours spent caring: 10-19	0.083	0.086
Hours spent caring: 20-49	0.004	0.095
Hours spent caring: 50+	0.122	0.105
Constant	2.358***	0.094

\*\*\* P<0.001 \*\*, P<0.01, \* P<0.05; OLS-regression. The models control for age, sex, education, employment status, and grossincome.

> No statistically significant relationship between informal caring and self-reported ill-health.

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> If anything informal carers are slightly <u>less</u> likely than non-carers to report ill health.



## **General Health in the NILS:**

DV: Self-reported ill-Health	β	S.E.
Hours spent caring: 1-19	-0.036***	0.005
Hours spent caring: 20-49	0.026**	0.009
Hours spent caring: 50+	0.054***	0.007
Constant	1.152	0.008

\*\*\* P<0.001 \*\*, P<0.01, \* P<0.05; Hierarchical linear model. The models control for age, sex, education, employment status, tenure, area-level (SOA)- income deprivation and Proximity to Services (NISRA 2010).

➤The number of hours spent caring matters: Those who spend less than 20 hours a week caring are less likely to report ill health than non-carers. However, above a cut-off of 20 hours the opposite is true.



- Caregivers report worse health the more income deprived the area is in which they live.
- Proximity to Services does not significantly moderate the relationship between caregiving and health.





# Informal Caregiving and Mental Health:



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## Experiences of Stress, Worry and Unhappiness

# Informal carers report higher levels of strain and stress in the HSNI than non-carers:

- 31.8% of informal carers said they worry quite a lot and 24.3% worry a great deal, while among non-carers only 26.3% worry quite a lot and 10% worry a great deal.
- 16.8% of informal carers said that they were taking medication for stress, anxiety or depression, while it is only 12.6% among non-carers.
- 28.4% of informal carers said they felt unhappier than usual, while 19.5% of non-carers made this statement.



## Mental Health: The HSNI GHQ-12-Score:

20.2% of Respondents to the NIHS had a GHQ-12 –score  $\geq$  4, indicating possible ill mental health.

Informal Carers are significantly more likely to suffer from ill mental health: 29% of informal carers have an GHQ-12 –score ≥ 4, while it is 19% among non-carers.

DV: Self-reported mental Health condition	β	S.E.
Hours spent caring: <10	0.189	0.240
Hours spent caring: 10-19	0.862***	0.014
Hours spent caring: 20-49	1.077***	0.336
Hours spent caring: 50+	1.996***	0.412
Constant	3.951***	0.336

Caregiving is associated with ill mental health only at a cut-off value of 10 and more hours caring.



### Mental Health: The NILS-BSO Data



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### Mental Health in the NILS:





### Self-reported Mental Health Condition- Marginal Effect of Informal Caring by Number of Carers in the Household









### Some first, preliminary findings on Mental Health Prescriptions and Informal Caregiving:

Percent who have been prescribed Anxiolytics and Antidepressants by the number of hours spent caring





### 'Has been prescribed Antidepressants' - Marginal Effect of Informal Caring by Number of Carers in the Household



spends 1 to 19 hours per week caring
spends 20 to 49 hours per week caring
spends 50 hours or more per week caring

Marginal effects from a binary logistic multilevel model. The models control for age, sex, migrant background, education, employment status, tenure, area-level (SOA)- income deprivation and Proximity to Services (NISRA 2010).









# Summary

-> Informal caregiving is related to a worse self-reported health and worse mental health for full-time carers and those who spend more than 20 hours per week caring.

The more time per week spent caring, the higher the risk of carer- strain and burden and the higher the risk of associated adverse effects on health and mental health. This is true for self-reported health, and for being prescribed of anxiolytics and antidepressants as the outcome-variables.

Carer's do report higher levels of strain and stress than non-carers, and this increases with their care-load. Carers with high workload also report higher levels of worry and unhappiness.

The finding ties in with previous findings by Chambers, Ryan, Connor (2001).





# Summary

However, carers spending moderate amounts of time caring are not worse off than non-carers. This concurs with previous findings (see Schulz and Sherwood 2008; Beach et al. 2000; O'Reilly et al. 2008).

The analysis of the NILS-data found carers spending less than 20 hours per week caring to even have better self-reported health and a lower risk of ill mental health than non-carers.

House-hold effects are <u>very</u> important: Carers with a high care-load (burden), living in multi-carer households are the most likely to suffer from ill health and ill mental health.

There are mediating and moderating effects of the carer-household that are not fully understood yet and this needs further inquiry.



# Summary

Area-level effects: Income deprivation matters for the relationship between caregiving and health, but less so for mental health (only weak moderating effect).

Area-remoteness (Proximity to services) does not significantly moderate the relationships between caregiving, health and mental health.

Carers seem to be facing the same challenges in rural as well as urban areas.





# Conclusion

The analysis of three data-sources has shown that an elevated risk of ill-health and mental health exists for carers with a high care-load (burden).

Research and Policy should pay particular attention to the support needs of caregivers with a high care-burden (above 20 hours caring per week), and those living in multi-carer households with a high care-burden.

Future studies should explore influencing factors of the household level. In particular, carer's and their families' experiences of delivering and receiving care, their (unmet) care-needs and challenges should be examined using qualitative studies that allow carers and their families to speak for themselves.

Mixed-methods approaches incorporating qualitative research techniques are particularly well-suited to expand the knowledge gained thus far.





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