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

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Introduction:

Northern Ireland's population, like the populations of all European societies, is ageing. Demographic estimates forecast that by 2025 the number of people aged 65 years and older will account for 20% of its population (Ahern and Hine 2012, 28). As a consequence, the provision of unpaid, informal care is of increasing importance for individuals, communities and service providers (Genet et al. 2011). The impact of informal caring on the caregivers' health and mental health is thus of great concern for policymakers.

A large literature on the matter yields inconclusive findings. While a majority of studies find informal caregiving to be related to ill health and ill mental health (Hirst 2005; Molyneux et al. 2008; Falloon, Graham-Hole, and Woodroffe 2009; Morimoto, Schreiner, and Asano 2003), others find the opposite (Beach et al. 2000; Schulz and Sherwood 2008) or report mixed results (O'Reilly et al. 2008; Hirst 2005).

On the one hand, informal caregiving is often associated with experiences of burden and strain (Morimoto, Schreiner, and Asano 2003; Ethers, Goodall, and Harrison 2008; McCullagh et al. 2005). Caregivers face stressful situations in dealing with a relative's health condition and care needs, and often dealing with the double or triple burden of childcare, care for an elderly relative or neighbor and handling a part-time or even full-time job. Experiences of loneliness and social isolation of carers have been reported as a problem (Chambers, Ryan, and Connor 2001; McCann, Ryan, and McKenna 2005) that can lead to depression. The stress of finding information on sources of support and feelings of uncertainty and insecurity has been found to be related to experiences of stress and anxiety (Chambers, Ryan, and Connor 2001).

On the other hand, caring for others can also be emotionally rewarding (Schwartz and Gidron 2002; Raschick and Ingersoll-Dayton 2004), as feelings of being helpful and being needed might lead to a positive sense of self-value and self-confidence.

The relationship appears to be influenced by various factors, such as the age and health condition of the cared-for, and the gender, age and socio-economic status of the carer. The household structure, number of children, availability of social and institutional support, and area-level socio-economic deprivation, proximity to services and rural-urban differences all seem to matter. Albeit the literature is large, there is still much work to be done with regards to the effects of socio-economic contexts of the household and area-level, such as Super Output Area (SOA)-level Income Deprivation and Proximity to Services (NISRA 2010). Furthermore, carers' health and mental health and their evaluations of how well existing policies meet their needs have to be studied longitudinally and results reported to policy makers early on, in order to monitor the success of existing policies and to be able to detect vulnerable groups and potentially unmet needs early on.

Regarding the measurement of the carers' health and mental health, various approaches have been used, from self-reported health to experimental settings, studies using questionnaire item-scales (Makowska et al. 2002; McCabe et al. 1996) and mental health medication uptake (Maguire et al. 2013). The latter approach has been found to deliver the highest degree of robustness, as drug prescriptions are an objective mental health measure.

However, usage of existing drug prescription data is still scarce and there is a scarcity of population-representative studies of the health and mental health of caregivers in Northern Ireland.

This briefing paper presents results from a secondary analysis of three data sources: the 2001 and 2011 Census variables within the Northern Ireland Longitudinal Study (NILS), a data-linkage of drug prescription data from the Enhanced

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Prescribing Database held by the Business Service Organization (BSO) to the NILS (2011), and mental health related survey questions in the 2011 Northern Ireland Health Survey (HSNI).

The Data

The first two data-sources offer insights into the subjective (self-reported) health and mental health and objective indicators of the mental health of caregivers (anxiety and depression) based on a large representative sample of the population of Northern Ireland. The Northern Ireland Longitudinal Study (NILS) is based on Health Card registrations and linked to 2001 and 2011 Census returns (Johnston, Rosato, and Catney 2010). This analysis uses the enumerated NILS population of adults aged 16 years and older with both 2001 and 2011 Census-links.

The third data source, the Northern Ireland Health Survey (HSNI) (N=4,085; 616 informal carers), is based on a random probability sample, representative of the population of Northern Ireland in 2010-2011. The Health Survey contains qualitative attitudinal survey questions on self-perceptions of experienced stress, strain, feelings of anxiety and unhappiness and the General Health Questionnaire (GHQ) 12-measure which is a 12-item scale measuring mental ill health that has been tried, tested and validated by researchers in various countries (Makowska et al. 2002; McCabe et al. 1996; Goldberg et al. 1997). The attitudinal and self-perception measures of the HSNI add a rich, qualitative dimension to the analysis, which the NILS does not contain.

The large sample size of the NILS (circa 28% of the population of Northern Ireland), on the other hand permits an analysis representative of carers in Northern Ireland, a sub-group of the population for which representative samples are rare, as the numbers tend to be very small in surveys. The two data sources thus complement each other and allow for robustness testing of key variables.

Furthermore, the NILS linked to drug-prescription data from the Enhanced Prescribing Database (BSO) offers a rare opportunity to study objective measures of mental ill-health: mental health drug prescriptions according to the classification of the British National Formulary (BNF-categories 1.4 anxiety medication prescriptions, and 4.3 antidepressant prescriptions), linked to the NILS, and thus representative of the Northern Ireland population.

This paper presents results from the first mental-health prescription data-linkage study on the mental health of caregivers, representative of the population of Northern Ireland.

The research question is under what circumstances is informal caregiving related to self-reported ill-health and ill mental health? How relevant are Area Deprivation and Proximity to Services (NISRA 2010)? How is informal caregiving related to the likelihood of individuals of being prescribed anxiolytics and antidepressants?

Results:

Caregiving per se is not found to be statistically significantly related to ill-health and ill mental health.

However, positive relationships were found between the number of hours spent caring per week and both ill self-reported health, ill self-reported mental health and being prescribed anxiolytics and antidepressants:

Caregivers for an ill or disabled relative or neighbor report worse health on average, are more likely to suffer from ill mental health and are more likely to be prescribed anxiolytics and anti-depressants, if their caring-responsibility exceeds 49 hours per week. For some measures, self-reported general ill health and being prescribed antidepressants the cut-off value at which caregiving was significantly related to ill health, is 20 hours of caring activity per week.

However, when mental health is measured by the self-perceptions used in the HSNI, the respondents exhibit signs of a low mental wellbeing (unhappiness, stress, strain) and ill mental health (GHQ-12-score) at a cut-off of 10 to 19 hours caring per week. Thus, caution is advised when looking at cut-off values of caring-responsibility. The cut-offs presented here are defined by the question's wording as they were asked on the Census 2001 and 2011 questionnaires, and they seem somewhat arbitrary. Furthermore, because not just the cut-offs, but also the mental health measure used in the HSNI differs from the measure used in the NILS, it cannot be determined whether the higher prevalence of ill mental health at a lower level of caring-responsibility is due to the lower cut-off or due to the qualitatively different mental health measure.

What can be said from both data-sources is that higher levels of caring-responsibility increase an individual's risk of developing ill health and ill mental health.

One mental health measure stands out: Prescription of antidepressants shows strikingly high levels for the Northern Ireland population as a whole, 19% of the population has been prescribed an antidepressant at least once in the period 2010 to 2011, and high levels especially for full-time carers, 22% of those who spend 20 to 49 hours caring and 25% of those who spend 50 hours or more per week caring have been prescribed an antidepressant at least once within this time-period. The finding of high antidepressant prescription rates for Northern Ireland in general is known from previous literature (Kelly et al. 2003) and it conforms with findings by colleagues using the same data-source for a different time-period (Maguire et al. 2013). A journalistic account coming to the same conclusion based on different data was recently reported on the BBC (BBC 2014). The findings presented here indicate that this is even more the case for informal carers.

The numbers for prescribed anxiolytics (between 2010 and 2011) are much lower: 6.7% of the overall population aged 16 years and older, and 5.9 % of those who spend one to 19 hours caring, 7.5% of those who spend 20 to 49 hours caring and 8.6% for those who spend 50 hours or more per week caring for an ill or disabled relative or neighbor. This may in part reflect differences in the prescription culture between anti-depressants and anxiolytics. Prescription of antidepressants might be more common as a general practice.

Interestingly, the statistical effect of hours spent caring per week on the self-reported general health and mental health in the NILS differs strongly by the number of carers in the household.

The analyses found significant moderation of the number of hours per week spent caring by the number of carers in the household. This indicates strong interrelations between individuals and their households – in particular, the analysis found that carers who have a high burden (50 hours and more care per week) and who live in multi-carer households are at a particularly high risk of experiencing both ill-health and ill mental health. For some measures, being prescribed antidepressants and self-reported ill mental health, those who spend 20-49 hours per week caring are at an elevated risk of ill-mental health as well.

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The findings demonstrate that carers within the context of carer-households need particular attention in order to understand which groups of the population are the most at risk of carer strain and of ill mental health and in order to detect their unmet support needs. 27% of carers represented in the NILS spend 50 hours or more caring, 32% of carers in the NILS live in households with two carers and 10% live in households with three or more carers.

Carers with a high caring responsibility who live in multi-carer households need particular attention, as they are found to be the most at risk of ill health and ill mental health related to carer strain and burden. The relationships found need further exploration in future studies using both quantitative and qualitative methods.

Future work on the NILS-prescription data-linkage study data will allow for a more fine-grained longitudinal analysis of the mental health of informal carers and thus try to tease out changes of carer-burden and mental health over time. In addition, qualitative interviewing of caregivers and their families in particular is a promising approach to shed additional light on household effects and on the support needs of carers in households, which cannot be explored further with the data presented here.

With regards to area-level effects, the data presented here found super-output area-(SOA)-level income deprivation to be related to an elevated risk of ill health and ill-mental health both among the population as a whole and among informal caregivers. Those who spend the most hours caring are at a higher risk of ill mental health the higher their SOA's deprivation score is. The remoteness of the respondents' areas of residence, measured by NISRA's Proximity to Services index (NISRA 2010) is statistically unrelated to the likelihood of carers of suffering ill self-reported health and ill mental health.

The risk of caregivers of suffering ill health and ill mental health does not differ statistically significantly between urban and rural areas in Northern Ireland.

Conclusion

The results presented in this briefing paper show that caregivers are at a higher risk of subjective ill health and of ill mental health the higher their caring-responsibility (as measured by the hours per week spent caring) is.

Particularly carers who spend more than 20 hours per week caring and who live in multi-carer households are at particular risk of carer strain, burden, anxiety and depression.

It is important for future research and policy to detect unmet needs particularly in the abovementioned groups of carers early on, in order to be able to deliver policies that offer adequate support and help prevent ill health and mental health. The need for continuous needs assessments and enhanced carer support is already acknowledged in the NHSCC Carers' Strategy (Northern Health and Social Care Trust (HSC) 2012) and the points mentioned in this strategy paper do find clear support in the data presented here.

Existing assessments of the needs of carers (JENDOUBI 2009; Department of Health, Social Services and Public Safety (NI) 2006) should furthermore target especially full-time carers and carers with caring-responsibilities of more than 19 hours per week. Also, the support needs of families with more than one carer need to be carefully studied. The findings so far indicate that these carer groups might be in need of additional support that helps reducing their burden. Existing arrangements like replacement care and respite care (Northern Health and Social Care Trust (HSC) 2012) might be strengthened and extended, to offer full-time carers additional support at an early stage, allowing them breaks and time for recreation, thus helping to prevent ill health and ill mental health.

References

- Ahern, Aoife, and Julian Hine. 2012. "Rural Transport – Valuing the Mobility of Older People." *Research in Transportation Economics*, Gender and transport: Transaction costs, competing claims and transport policy gaps, 34 (1): 27–34. doi:10.1016/j.retrec.2011.12.004.
- BBC. 2014. "NI Anti-Depressants at 'World High,'" November 16, sec. Northern Ireland. <http://www.bbc.co.uk/news/uk-northern-ireland-30073669>.
- Beach, Scott R., Richard Schulz, Jennifer L. Yee, and Sharon Jackson. 2000. "Negative and Positive Health Effects of Caring for a Disabled Spouse: Longitudinal Findings From the Caregiver Health Effects Study." *Psychology & Aging* June 2000 15 (2): 259–71. doi:10.1037/0882-7974.15.2.259.
- Chambers, M., Assumpta Ann Ryan, and S. Connor. 2001. "Exploring the Emotional Support Needs and Coping Strategies of Family Carers." *Journal of Psychiatric and Mental Health Nursing* 8: 99–106.
- Department of Health, Social Services and Public Safety (NI). 2006. "Caring for Carers. Recognising, Valuing and Supporting the Caring Role." HSC NI Belfast.
- . 2011. *The Northern Ireland Health Survey, 2010-2011*. 7258. Belfast: Northern Ireland Statistics and Research Agency. Central Survey Unit.
- Etters, Lynn, Debbie Goodall, and Barbara E. Harrison. 2008. "Caregiver Burden among Dementia Patient Caregivers: A Review of the Literature." *Journal of the American Academy of Nurse Practitioners* 20 (8): 423–28. doi:10.1111/j.1745-7599.2008.00342.x.
- Falloon, Ian R. H., Victor Graham-Hole, and Robert Woodroffe. 2009. "Stress and Health of Informal Carers of People with Chronic Mental Disorders." Research-article. July 6. <http://informahealthcare.com/doi/abs/10.3109/09638239309018399>.
- Genet, Nadine, Wienke GW Boerma, Dionne S. Kringos, Ans Bouman, Anneke L. Francke, Cecilia Fagerström, Maria G. Melchiorre, Cosetta Greco, and Walter Devillé. 2011. "Home Care in Europe: A Systematic Literature Review." *BMC Health Services Research* 11 (1): 207. doi:10.1186/1472-6963-11-207.
- Goldberg, D. P., R. Gater, N. Sartorius, T. B. Ustun, M. Piccinelli, O. Gureje, and C. Rutter. 1997. "The Validity of Two Versions of the GHQ in the WHO Study of Mental Illness in General Health Care." *Psychological Medicine* 27 (01): 191–97. doi:null.
- Hirst, Michael. 2005. "Carer Distress: A Prospective, Population-Based Study." *Social Science & Medicine* 61 (3): 697–708. doi:10.1016/j.socscimed.2005.01.001.
- JENDOUBI, CHRISTINE. 2009. *CIRCULAR HSS (ECCU) 2/2009: REGIONAL CARER'S SUPPORT AND NEEDS ASSESSMENT TOOL*. <http://www.dhsspsni.gov.uk/eccu2-09.pdf>.
- Johnston, Fiona, Michael Rosato, and Gemma Catney. 2010. *The Northern Ireland Longitudinal Study – An Introduction. NILS Working Paper 1.0*. Belfast: NILS Research Support Unit.
- Kelly, Christopher B., Tanzeel Ansari, Thérèse Rafferty, and Mike Stevenson. 2003. "Antidepressant Prescribing and Suicide Rate in Northern Ireland." *European Psychiatry* 18 (7): 325–28. doi:10.1016/j.eurpsy.2003.03.005.
- Maguire, Aideen, Carmel Hughes, Chris Cardwell, and Dermot O'Reilly. 2013. "Psychotropic Medications and the Transition Into Care: A National Data Linkage Study." *Journal of the American Geriatrics Society* 61 (2): 215–21. doi:10.1111/jgs.12101.
- Makowska, Zofia, Dorota Merecz, Asnieszka Moscicka, and Woj Kolasa. 2002. "The Validity of the General Health Questionnaires, GHQ-12 and GHQ-28, in Mental Health Studies of Working People." *International Journal of Occupational Medicine and Environmental Health* 15 (4): 353–62.
- McCabe, C. J., K. J. Thomas, J. E. Brazier, and P. Coleman. 1996. "Measuring the Mental Health Status of a Population: A Comparison of the GHQ-12 and the SF-36 (MHI-5)." *The British Journal of Psychiatry* 169 (4): 516–21. doi:10.1192/bjp.169.4.516.
- McCann, Siobhan, Assumpta Ann Ryan, and Hugh McKenna. 2005. "The Challenges Associated with Providing Community Care for People with Complex Needs in Rural Areas: A Qualitative Investigation." *Health & Social Care in the Community* 13 (5): 462–69. doi:10.1111/j.1365-2524.2005.00573.x.
- McCullagh, Emily, Gavin Brigstocke, Nora Donaldson, and Lalit Kalra. 2005. "Determinants of Caregiving Burden and Quality of Life in Caregivers of Stroke Patients." *Stroke* 36 (10): 2181–86. doi:10.1161/01.STR.0000181755.23914.53.
- Molyneux, G. J., G. M. McCarthy, S. McEniff, M. Cryan, and R. M. Conroy. 2008. "Prevalence and Predictors of Carer Burden and Depression in Carers of Patients Referred to an Old Age Psychiatric Service." *International Psychogeriatrics* 20 (06): 1193–1202. doi:10.1017/S1041610208007515.

- Morimoto, Tomoko, Andrea S. Schreiner, and Hitoshi Asano. 2003. "Caregiver Burden and Health-related Quality of Life among Japanese Stroke Caregivers." *Age and Ageing* 32 (2): 218–23. doi:10.1093/ageing/32.2.218.
- NISRA. 2010. *Northern Ireland Multiple Deprivation Measure 2010*. Belfast: Northern Ireland Statistics and Research Agency (NISRA).
- Northern Health and Social Care Trust (HSC). 2012. *NHSCT Carer's Strategy 2012-2017*. Belfast. http://www.northerntrust.hscni.net/images/NHSCT_Carers_Strategy.pdf.
- O'Reilly, Dermot, Sheelah Connolly, Michael Rosato, and Chris Patterson. 2008. "Is Caring Associated with an Increased Risk of Mortality? A Longitudinal Study." *Social Science & Medicine* 67 (8): 1282–90. doi:10.1016/j.socscimed.2008.06.025.
- Raschick, Michael, and Berit Ingersoll-Dayton. 2004. "The Costs and Rewards of Caregiving Among Aging Spouses and Adult Children*." *Family Relations* 53 (3): 317–25. doi:10.1111/j.0022-2445.2004.0008.x.
- Schulz, Richard, and Paula R. Sherwood. 2008. "Physical and Mental Health Effects of Family Caregiving." *The American Journal of Nursing* 108 (9 Suppl): 23–27. doi:10.1097/01.NAJ.0000336406.45248.4c.
- Schwartz, Chaya, and Ronit Gidron. 2002. "Parents of Mentally Ill Adult Children Living at Home Rewards of Caregiving." *Health & Social Work* 27 (2): 145–54. doi:10.1093/hsw/27.2.145.

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Appendix

NLS 2011 with linked BSO drug-prescription records	DV: Self-reported mental Health condition		DV: Has been prescribed Anxiolytics		DV: Has been prescribed Antidepressants	
	β	S.E.	β	S.E.	β	S.E.
Hours spent caring: 1-19	0.016	0.029	-0.025	0.027	0.062***	0.016
Hours spent caring: 20-49	0.032	0.043	0.077	0.043	0.130***	0.028
Hours spent caring: 50+	0.209***	0.031	0.079*	0.036	0.214***	0.021
Constant	-2.894***	0.041	-3.753***	0.043	-2.045***	0.052

NLS 2011 with linked BSO drug-prescription records	DV: Self-reported mental Health condition		DV: Has been prescribed Anxiolytics		DV: Has been prescribed Antidepressants	
	β	S.E.	β	S.E.	β	S.E.
Hours spent caring: 1-19	-0.792***	0.032	-0.168***	0.032	-0.115***	0.002
Hours spent caring: 20-49	-0.447***	0.045	0.076	0.046	0.101***	0.029
Hours spent caring: 50+	-0.182***	0.033	0.215***	0.036	0.290***	0.023
No of Carers in the household	0.397***	0.011	0.050***	0.013	0.077***	0.008
Constant	-2.757***	0.018	-4.066***	0.025	-2.045***	0.052

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