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The impact of caring

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The impact of caring

Paula Devine and Ann Marie Gray

Unpaid carers play a vital role in supporting our health and social care system. This contribution is recognised in government strategic frameworks (DHSSPS, 2006; 2009). Buckner and Yeandle (2015) estimate that the support provided by the 220,500 carers in Northern Ireland is £4.6 billion per year, which is similar to the entire 2016/17 Stormont health budget (Detail Data, 2016).

Surveys are important in recording the extent of caring responsibilities across Northern Ireland and how people feel about caring, in order to feed into public and policy discussions. Thus, the **Northern Ireland Life and Times (NILT) survey**, and its predecessor the Northern Ireland Social Attitudes survey, included questions on unpaid care in 1994, 2006 and 2010 (see Evason, 2007; Ferguson and Devine, 2011). The 2015 NILT survey is the latest to do so, and 1,202 adults living across Northern Ireland took part. This Research Update focuses on data from the 2015 survey, with a particular focus on the impact of caring on carers, and sets the data in the context of recent and forthcoming policy developments.

Who cares?

Approximately one in ten NILT respondents (9%) said that they look after or give special help to someone living with them who is sick, disabled or elderly. A similar proportion (9%) do this for someone not living with them. Ten

people provided care both inside and outside their home. This means that that, overall, 17 per cent of NILT respondents in 2015 are carers, and this is higher for women (21%) than men (13%). Whilst similar proportions of men and women provide care for someone living with them (8% and 11% respectively), women were more likely to provide care for someone in another household (12% and 6% respectively). One quarter of carers (25%) said that they themselves had a long term physical or mental health condition or illness, which is higher than for non-carers (20%).

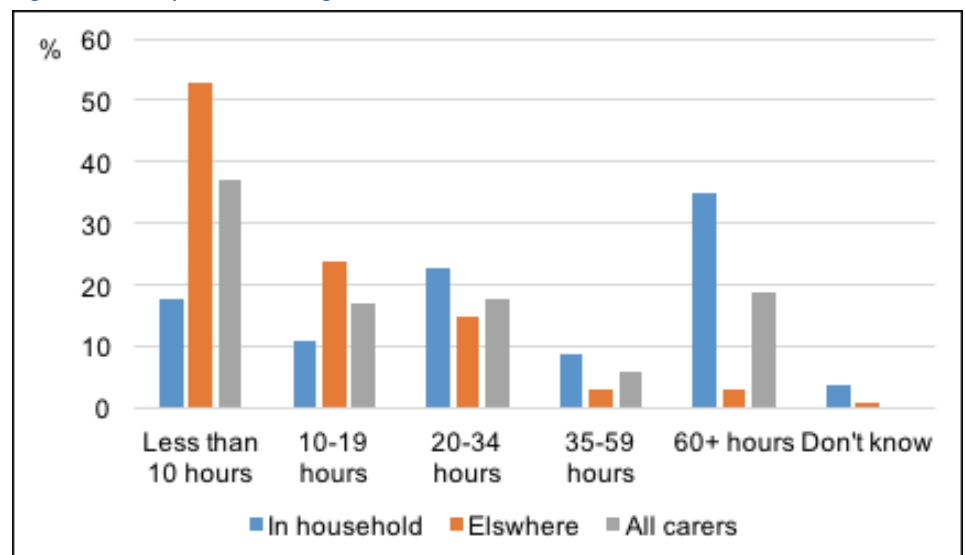
per week caring for. The vast majority of support was given to family members, with only a very small proportion (5%) looking after a friend or neighbour. The most identified group were parents or parents in law (44%), followed by spouse or partner (29%), child (10%) and other relative (13%). One common perception is that older people receive care provided by younger people. Within NILT, however, 16 per cent of respondents aged 65 years or over are carers. Of these, one quarter were caring for their own parent/parent in law.

The most frequent reason for providing care was physical disability (57%), followed by physical illness (51%) and old age or frailty (50%). Dementia (16%), mental illness (10%) and learning disability (9%) were also identified.

Who is receiving care?

The survey asked carers to think about the person that they spend most hours

Figure 1: Hours per week caring



Volume of care

As seen in Figure 1, the volume of time spent caring varies greatly. As might be expected, this is very much related to whether the carer is providing care for someone living with them or not. One in four carers (25%) taking part in NILT provided at least 35 hours of care, which can be seen as equivalent to a full time job. Importantly, 35 hours is also the threshold above which carers may be eligible to apply for Carer's Allowance, although this is dependent upon other eligibility criteria related to benefits and income.

Ferguson and Devine (2011) highlighted that many of the potential negative impacts of caring take effect after 20 hours per week. Four out of ten carers (43%) identified in the 2015 survey provide this intensity of care, including nearly two thirds of those providing care for someone living in the same household. These impacts affect emotional and physical health, finances, and working life.

Emotional impact

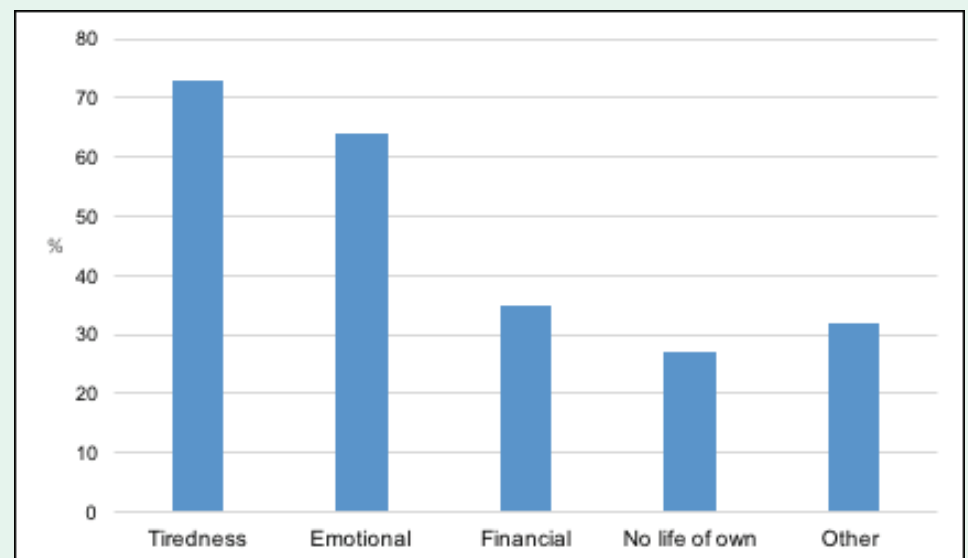
In 2010, NILT introduced questions that explored the difficulties and satisfactions experienced in carers' lives. Table 1 shows that in 2015, carers experienced a range of mixed emotions, and this very much matches the findings of the 2010 survey. The majority of carers said that they are happy that they can help someone, including 70 per cent who felt this 'most of the time'. Related to this, three quarters of respondents said that they felt that they are giving something back.

At the same time, there was also acknowledgement of the difficulties associated with caring for a family member or friend. Nearly two thirds of carers said that they felt under pressure (21% 'most of the time', and 43% 'sometimes'). Moreover, 21 per cent of carers felt resentment at some time.

Table 1: Feelings of carers

	%			
	Most of the time	Sometimes	Not at all	Don't know
Happy that you are able to help someone	70	25	5	1
Giving something back	44	32	20	4
Under pressure	21	43	36	1
Resentment	2	19	79	1

Figure 2: Type of pressure felt by carers*



*As a percentage of carers feeling pressure 'most of the time' or 'sometimes'

Under pressure

Given the feelings of pressure identified in the 2010 survey, new questions in 2015 explored this further among carers who felt pressure 'most of the time' or 'sometimes'. Figure 2 demonstrates that the most frequent stressor was tiredness (73%), followed by emotional pressure (64%). Other pressures (financial pressure, feeling of having no life of your own, and pressure in other ways) were identified by a significant minority – at least one in four. This relates to research findings by Carers UK in 2016, which indicate that one quarter (26%) of carers are in debt as a result of their caring responsibilities. The NILT data also reflects the multiple types of stress that

carers face – one in four carers identified at least three types of pressure.

Employment

Research by Kate Jopling in 2016 on combining work and caring showed that many carers wanted to remain in work for financial, health and wellbeing reasons. However, their ability to take on paid work was affected by barriers such as lack of flexibility in the workplace, and poor attitudes towards carers. These strains resulted in some carers being forced to withdraw from work, resulting in financial 'scars', as well as negative effects on health and wellbeing.

Just under one half of carers taking part in the 2015 NILT survey were in work

Table 2: Impact of caring on work

	%		
	Living in household	Not living in household	All carers
Unable to work at all	31	8	20
Unable to do as much paid work as you might like to do	13	8	11
Or, this doesn't prevent you from working?	56	80	68
Don't know	0	3	1

(46%), and they were less likely than other carers to provide care for at least 35 hours per week (18% and 31% respectively). Most carers (68%) said that the time they spend caring doesn't prevent them from working – see Table 2. Nevertheless, 20 per cent said that they were unable to work at all, and a further 11 per cent said that they were unable to do as much paid work as they might like to do. These latter figures are higher among those respondents providing care for someone living with them, no doubt due to the higher level of intensity of care.

Discussion

The NILT data provide an important snapshot of caring provided by family and friends across Northern Ireland in 2015. The fact that 19 per cent of carers are providing at least 60 hours of care per week shows how essential carers are to the health and social care system.

Whilst governments across the UK have published strategies aimed at supporting carers, the NILT findings show there is still cause for concern. In Britain, legislation to reform adult social care law has resulted in new entitlements to social care for users and carers. New national eligibility criteria for users and carers in England (DoH, 2014) establishes a minimum threshold. Once carers are assessed as crossing this, local authorities have a

duty to meet the assessed needs. These duties include promotion of a carer's 'wellbeing', with wellbeing principles part of the eligibility criteria. Recent data (Carers Trust, 2016) identified that many carers are still not aware of their rights and have not been offered an assessment. But there is also indication of positive impacts of the legislation, including better assessments and more appropriate support. In Scotland, the Carers Scotland Act 2016 places a similar duty on local authorities. The need for a new legislative framework in Northern Ireland to provide clarity on entitlement to services for users and carers has been recommended (Duffy et al., 2015).

An expert panel, chaired by Professor Rafael Bengoa, examining the future configuration of health services in Northern Ireland reported that '...the largest group ... of staff delivering care services in Northern Ireland is unpaid' and that 'engaging and supporting carers is a fundamental aspect of maintaining service users within their own home and it is essential that the HSC improves its performance in this area' (DoH, 2016a, p.28). The Department of Health (2016b) has acknowledged the need to improve support for carers, noting that this would be considered in proposals on the reform of adult social care to be published in 2017.

Social policies outside of health and social care also have consequences for carers. While Carer's Allowance is not directly affected by the most recent welfare reform policy, other changes can have a knock on effect on entitlement. The move from Disability Living Allowance to the Personal Independent Payment (PIP) means that if a person that a carer is caring for loses entitlement to their disability benefit as a result of re-assessment for PIP, the carer is no longer entitled to Carer's Allowance. In Northern Ireland, as part of the mitigation package put in place to ameliorate the impact of welfare reform, carers affected in this way will receive a supplementary payment to cover their financial loss for a period of a year. Carers may also be affected by the increased conditionality attached to receipt of Universal Credit, which could make combining care and work more difficult.

The NILT data highlights the complexities of the responsibilities and pressures associated with carers' lives and provides new evidence of the impact that these roles have on carers. It therefore makes an important contribution to debates about future health and social care policy, employment policy and assessments of the impact of welfare reform.

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Key points

- 17% of respondents are carers, including 21% of women and 13% of men.
- Care is most often provided for parents/parents in law.
- 25% of carers provide care for 35 hours per week or more.
- 64% of carers said that they feel under pressure most or some of the time, especially tiredness and emotional pressure.
- However, 95% of carers are happy to be able to help, and 76% feel that they are giving something back.
- 68% said that caring doesn't prevent them from working, although this is lower among carers living with the person they provide care for.

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The **Northern Ireland Life and Times (NILT) survey** is carried out annually and documents public opinion on a wide range of social issues. NILT is a joint project of the two Northern Ireland universities and aims to provide an independent source of information on what the public thinks about the social issues of the day.

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