

**Health and Well-being of Family Carers in Ireland:
Results of a survey of recipients of the Carer's Allowance**

Executive Summary

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There is little Irish research that documents the self-reported health status of family carers. This research published by Care Alliance Ireland examines the relationship between caring and health and well-being and offers suggestions for future policy development.

Low-income, full-time family carers are hypothesised to be a group that is particularly vulnerable to poor health. A sample of 10 per cent (2,834) of the recipients of the state Carer's Allowance (CA) payment was surveyed in April 2007 using a self-administered questionnaire, with the sample being representative of CA recipients in terms of marital status, age, gender and county of residence. This sample is not however necessarily representative of the entire family carer community in the Republic of Ireland. Eligibility for the Carer's Allowance is dependent on several criteria; significantly that the caring is full-time and that income is below a certain level. The 2006 Census figures indicate that three quarters of family carers report providing care on a part-time basis (i.e. less than 43 hours per week). This group of family carers sampled, therefore, may be considered to be a sample of full-time carers with low to moderate income. A response rate of 50 per cent was achieved. Just over 80 per cent of respondents were female and 20 per cent were male.

It was considered important to compare key responses of the questionnaire with a wider population sample, and for that purpose the responses were compared with the SLÁN 02 survey, based on a national population. In order to ensure accurate comparison, the data from the SLÁN '02 survey were weighted for various factors including age, gender and educational attainment.

Findings

Carers presented a considerably less positive picture of quality of life in comparison to the general population. In the SLÁN survey, 27.7 per cent

reported themselves to have a very good quality of life whilst in the carers survey only 16.0 per cent did so. At the other end of the spectrum, carers were a lot more likely to report their quality of life to be neither good nor poor, and also more likely to report it to be poor or very poor.

Carers were less likely to report themselves in 'very good' or 'excellent' health as opposed to 'good' health compared to the general population. Amongst the carers, 36 per cent said they were in very good or excellent health, whilst for the SLÁN survey 44.9 per cent said they were in very good or excellent health. The data does show a statistically significant pattern of carers reporting being less healthy than do the general population. A majority of carers (70.1 per cent) were either satisfied or very satisfied with their health. Comparisons with SLÁN found no significant difference between carers and the general adult population in this regard.

Reflecting on the profile of recipients of the Carer's Allowance, the carers in this survey were mainly concentrated in the 35 to 64 years age range. Ninety per cent were providing at least 40 hours of care per week, with the majority of these providing more than 59 hours per week. There was a mix of caring situations, mainly falling into three groups: people caring for their children (both young and grown up), for their spouse/partner and for a parent/parent-in-law.

More than one-half were caring for someone aged 60 years or older, either people caring for a parent/parent-in-law or one partner in an older couple caring for the other. As regards type of care needs, nearly one-half were caring for someone described as having a physical disability (this included older people with physical disabilities also), one-in-six were caring for someone described as having an intellectual disability and almost one-in-nine were caring for someone with both.

The majority of respondents are relying solely on the Carer's Allowance as an income. Whilst the payment is low relative to the minimum wage or the average industrial income, this does not necessarily point to the individual experiencing

income poverty, as this is a complex area. In addition we do not know the extent to which other household members are supplementing the household income.

Other key findings

- Two-in-five carers reported having experienced stress/ nervous tension and one-in-nine carers reported having their daily activity limited by ill-health or disability in the past twelve months
- When family carers were asked to report negative impacts of caring on their health and well-being, nearly one-third reported that their health had suffered due to their caring responsibilities and almost one-half stated their leisure or recreational activities had been limited quite a lot or a great deal
- Emotional issues, stress, being constantly on-call and lack of sleep/ tiredness were frequently mentioned amongst the most difficult aspects of caring
- Talking to friends and watching TV were the most frequently mentioned coping strategies for carers, followed by praying/faith and exercise. Amounts of support from family and others varied widely, with about one-half of carers being without a major source of support and about one-quarter with little or no support at all. Carers, when compared with the weighted SLÁN 02 sample, reported considerably lower levels of overall support
- Carers were significantly more likely to be smokers and less likely to be regular drinkers than the general population, and seem to have about the same likelihood of being injured.

Multivariate analysis

- Two socio-demographic factors were also found to be important. Firstly, being a male was associated with a 1.6 times greater likelihood of lower quality of life than being a female
- Secondly, not having a spouse/partner in full-time employment was associated with a 1.9 times greater likelihood of lower quality of life

- The results show that likelihood of reporting that health has suffered was strongly associated with whether or not caring impacts on leisure. Where leisure is limited a great deal, negative health impacts were 7.8 times more likely to be reported than where leisure is not affected at all
- Significantly increased likelihood of negative health impacts were also found when caring is reported to cause stress (3.2 times more likely), lack of sleep/ tiredness (2.7 times more likely), emotional strain (2.7 times more likely) and isolation (1.7 times more likely)
- The results again show the importance of impacts of caring on leisure time. Where leisure is limited a great deal there was a 3.3 times greater likelihood of lower quality of life being reported in comparison to where leisure is not limited at all. Significantly increased likelihood of lower quality of life was also found where caring causes stress (1.9 times more likely), isolation (1.9 times more likely), lack of sleep/ tiredness (1.7 times more likely) and emotional strain (1.5 times more likely)
- The extent of support available was also a key factor. Where there is little or no support there was a 2.7 times greater likelihood of lower quality of life being reported in comparison to where there is more than one good source of support
- Talking with friends as a coping strategy was strongly associated. Where this strategy is not reported there was a two times greater likelihood of lower quality of life being reported. However, where use of prayer/faith as a coping strategy is reported there was a 1.5 times greater likelihood of reporting lower quality of life
 - Finally, having had an injury (other than a back injury) in the past two years was associated with a 2.1 times greater likelihood of reporting lower quality of life.

The extent of limitation posed by caring on leisure/recreation appeared to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality of life for

carers. Those caring for longer hours, being constantly on call and caring for certain types of needs (particularly where there are specific physical and/or intellectual disabilities combined with old age) were especially likely to report substantial limitations on their leisure/recreation activities. Stress, lack of sleep/ tiredness, emotional strain and isolation were also important factors in the likelihood of negative impacts on health. On the positive side, availability of good support and talking to friends as a coping strategy were used by family carers to keep going.

Key recommendations

1. Increase opportunities for breaks for family carers

When caring severely restricts leisure/recreational opportunities family carers are a lot more likely to report that their health has suffered and/or a lower quality of life. This emphasises the importance of policy efforts to ensure that carers have breaks and time to themselves. Respite services have a key role to play in this, as well as active efforts to encourage and support carers to have a life beyond caring.

Alongside restricted leisure time, lack of sleep/ tiredness is a big factor in the likelihood of carers experiencing negative impacts of caring on their health and well-being. Policy efforts should therefore give attention to implementing supports that help carers to get enough sleep and rest and not have an unreasonable care burden to manage. Night-time respite services could have an important role in relation to lack of sleep. There are also promising developments in technologies that can monitor the person being cared for so that the carer can get enough sleep. More generally, sufficient home care support needs to be provided to avoid carers becoming over-burdened and over-tired. In addition, it is vital that respite services respect the needs of both the carer and the care recipient.

2. Promoting awareness of family carers and their support needs

Carers who have little or no support from family, friends or others are especially likely to report low quality of life, as are carers who report isolation. Policy efforts

aimed at increasing the general awareness of caring and the importance of providing support (both practical and emotional) to carers could have an important role to play.

3. Reducing carer stress

Stress and emotional strain are frequently reported by carers and these, in turn, are linked to a greater likelihood of carers reporting that their health has suffered and/or a lower quality of life. Policy efforts aimed at reducing the stress and emotional strains on carers are therefore important. Improvement of existing services and supports for carers would be an important first step. With the recent provision of significant resources for family carer training, it is important that any training models proposed and accepted are evidence-based. Evaluations of such interventions should inform the more widespread roll-out of such programmes as appropriate.

4. Carer entitlements and income

Whilst the entire sample surveyed was in receipt of Carer's Allowance, the vast majority of the group had no other income. Low income, coupled with long hours of caring that restricts carers' opportunities to take up employment, make them a group at risk in terms of likelihood of experiencing income poverty. Future carers policy would need to take into account the loss of economic opportunities due to caring work and also the cost of caring where in some circumstances carers have to cover the extra costs of disability when caring for a disabled relative.

5. Targeting male carers

This research has identified male carers being at particular risk of reporting both lower quality of life and being less satisfied with their health than female carers. Innovative ways of identifying, engaging with and supporting male carers need to be actively considered.