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ORIGINAL RESEARCH

Widening the net: exploring social determinants of burden of informal carers

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Objectives. Providing care for a person with dementia or other chronic illness at home often places stress on the primary caregiver. In an Irish population, ~67% of carers reported experiencing extreme physical or mental tiredness. This study aimed to identify factors that influence carer burden and identify the sub-populations of carers who are most susceptible to burden.

Methods. Consecutive carers referred to a local carers' support organisation completed the following measurements: the Neuropsychiatric Inventory, Zarit Burden Interview, Social Network Index, General Health Questionnaire, Short Form Survey, Hamilton Depression Rating Scale, Brown's Locus of Control scale and provided demographic data on themselves and their patient.

Results. The sample consisted 53 carers, mean age: 64.5 ± 11.7, of whom 43 (81.1%) were females. A linear regression model found significant independent ($p < 0.05$) factors for carer burden were: increased behavioural problems of the patient, carer characteristics including female gender, younger age, high number of contacts, lower physical functioning and emotional problems, while protective factors were marriage and higher number of embedded networks.

Conclusions. The ability to predict which carers are more susceptible to burden allows service providers to more quickly and accurately identify 'higher risk' carers, facilitating routine check-ups by physicians and carer support services.

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Key words: Carer burden, informal carers, resilience, risk factors for burden, social networks.

Introduction

Informal Carers are defined as non-professionals who provide unpaid help and support to those who are disabled or chronically ill (Singleton *et al.* 2002) and who may spend in excess of 100 hours/week in their supportive role (McDaid, 2001). However, the role of caring may also have negative consequences frequently referred to as 'caregiver burden'. Caregiver burden refers to the caregiver's perceived emotional, social, and financial consequences of care provision (Zarit *et al.* 1980).

Providing care for a person with dementia or other chronic illness at home often places stress on the primary caregiver (Brodaty & Donkin 2009). The stress can have many causes including the need to be available to the person with the chronic illness at all times as well as problems with communication and behavioural disturbances associated with mental or physical illness (Grant *et al.* 2003). Stress of caring can also be exacerbated by lack of a supportive response from local health and social services, and by lack of support and sometimes criticism from other family members (Shaji *et al.* 2003). Such stress can have a range of adverse effects including the breakdown of the relationship between patient and caregiver, a poorer quality of care and physical and psychological morbidity for both the patient and caregiver (Neufeld & Harrison 2003; Pinquart & Sörensen, 2006; Parker *et al.* 2008). In addition, emotional distress is an independent risk factor for mortality and stroke in caregivers (Schulz & Beach, 1999) and in some cases violence and other forms of abuse may be precipitated (Maayan *et al.* 2014).

In addition to psychological stress and burnout carers generally report poor health and greater use of the health services compared to those non-caregiving matching controls (Kiecolt-Glaser *et al.* 1991; Baumgarten *et al.* 1992; Wawrziczny *et al.* 2016).

The carer's burden is influenced by many factors; for instance, behavioural disturbances in the care recipient are associated with carer burden (Black & Almeida, 2004), lack of social support (Gaugler *et al.* 2008), the level of self-efficacy of the carer (Gilliam & Steffen, 2006) as well as sociodemographic factors (Luchesi *et al.* 2016) including the age of the carer (Pinquart & Sörensen, 2006), gender and country (Prince *et al.* 2012).

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However, to be a caregiver can also be rewarding (Andrén & Elmståhl, 2005) and can have positive effects (Roth *et al*. 2009, 2013; Buyck *et al*. 2011). In addition, not all the studies have found a causal relationship of specific behavioural problems and carer burden (Ornstein & Gaugler, 2012) and a weak association between severity of cognitive or functional impairment and carer burden has also been reported (Brodaty & Hadzi-Pavlovic, 1990). Given those observations the term of resilience has been introduced and a number of factors related have been investigated including social support, relationships, utilisation of services, self-esteem and others (Donnellan *et al*. 2015; Joling *et al*. 2016).

There are ~274 000 informal carers in Ireland (Care Alliance Ireland, 2015). In a study commissioned by the Department of Public Health (1999) in 1999, which investigated carer burden amongst carers residing in western rural counties of Ireland (Galway, Mayo and Roscommon) it was found that ~67% of carers experienced extreme physical or mental tiredness, 43% reported a decrease in their quality of life and 28% reported a deterioration in their physical health since taking on a caregiving role (DPH, 1999).

A previous study in the same geographical area (Molyneux *et al*. 2008) has found high levels of depression in the primary carers of community-dwelling patients attending an old age psychiatric service. The patients' behaviour and their cognitive and functional ability conferred greater risk of carer depression or strain than their diagnosis. Those findings were in concordance with other findings from different areas and countries which make the carers stress an universal phenomenon.

Carers can also experience burden when the person they are caring for moves from home to an acute in-patient setting. Amongst carers of patients with psychiatric difficulties it is often the carer who steps in when the person becomes acutely unwell (de Haan *et al*. 2002). In a recent paper by Ranieri *et al*. (2016) the level of caregiver burden and psychological distress were explored in those carers of patients who had an admission to an acute psychiatric ward. They showed that the legal status of the patient did not affect the degree of burden experienced but that 15% of carers in this study reported high levels of psychological distress.

In carers of those patients with chronic medical illnesses such as colorectal cancer it has been shown that carers experience high degrees of burden. In a recent paper by Maguire *et al*. (2016) the authors developed a predictive model which aimed to identify those most at risk, with time spent in the caring role identified as the most consistent predictor.

Furthermore local research into carers' needs and burden of care emphasises the need to create individualised carer support interventions in order to minimise burden and reduce patient admissions and consequently expenditure to long-term care services (Okorie *et al*. 2010).

Therefore, the main aim of this study is to explore carer burden, in carers of adults with mental health difficulties (including dementia) in the North West. Secondary aims of the study are to explore resilience factors including the influence of locus of control on carer burden, social relationships, personal and social factors, and utilisation of respite care after controlling for the degree of behavioural problems of the person being cared for that impact upon carer burden.

Methods

Setting-participants

This study was a cross-sectional study conducted in a community setting. Informal carers who were referred to a local carers support organisation were eligible for this assessment. There were no further inclusion or exclusion criteria employed. Carers were contacted over the phone, consent for participation was obtained and a meeting was arranged for a face-to-face interview to take place either in the carer's home, or the carers support organisation facilities.

Measurements

Demographics: demographics (age, gender, marital status, relationship) for both carer and person cared for were collected. Also, diagnosis (es) and time since the person was first diagnosed were collected. In addition, information on the use of respite care was gathered.

Carers were asked to complete the following assessments related to carer distress and burden: Neuropsychiatric Inventory (NPI) (Cummings, 1997), the Social Network Index (SNI), General Health Questionnaire (GHQ-12), Short Form Survey (SF-12 v.2), the Zarit Burden Interview (ZBI), Locus of control (Brown) and Hamilton Depression Rating Scale (HDRS).

- NPI (Cummings, 1997): This consisted of 10 behavioural and two neurovegetative (sleep, appetite) domains. For each behavioural domain there are four scores: frequency, severity, total (frequency × severity) and caregiver distress. The purpose of the NPI was to obtain information on the presence of psychopathology in patients with brain disorders. The NPI was developed for application to patients with Alzheimer's disease and other dementias, but it can be used in the assessment of behavioural changes in other conditions (Lai, 2014). The total NPI score is the sum total of all of the individual domain scores with a range of 0–144 (higher scores indicate more behavioural problems). The caregiver distress level does not count towards the total NPI score. The amount of time required to complete the NPI is around 20–30 minutes.

- SNI: It assesses participation in 12 types of social relationships. These include relationships with a spouse, parents, parents-in-law, children, other close family members, close neighbours, friends, workmates, schoolmates, fellow volunteers, members of groups without religious affiliation and religious groups. One point is assigned for each type of relationship (possible score of 12) for which respondents indicate that they speak (in person or on the phone) to persons in that relationship at least once every 2 weeks. The SNI can produce three separate measurements. (a) Number of high-contact roles (network diversity). This is the number of social roles in which the respondent has regular contact (i.e. at least once every 2 weeks) with at least one person. (b) Number of people in the social network, which is the total number of people with whom the respondent has regular contact (i.e. at least once every 2 weeks); and (c) number of embedded networks which is the number of different network domains in which a respondent is active. The maximum possible is eight. They are: family, friends, church, school, work, neighbours, volunteering and groups. To receive a point for a domain, a respondent must have at least four high-contact people within that domain (Cohen *et al*. 1997).
- GHQ-12: The GHQ-12 was developed by Goldberg & Blackwell (1972) and has been excessively used as a reliable screening instrument for psychological distress in adults.
- SF-12 v.2: The 12-item SF-12 v.2, derived from the SF-36, and has been demonstrated to be reliable and valid in clinical and population-based samples (Lundberg *et al*. 1999). The SF-12 assesses eight domains. Physical functioning, role limitation as a result of physical health, role limitation as a result of emotional health, pain, mental health, vitality, social functioning and general health. The scores are transforming to a 0–100 *T*-scores. Physical and Mental Health Composite Scores (PCS and MCS) are computed using the scores of the twelve items above and range from 0 to 100, where a zero score indicates the lowest level of health measured by the scales and 100 indicates the highest level of health (Ware *et al*. 2002).
- The ZBI: It is a popular caregiver self-report measure originated as a 29-item questionnaire (Zarit *et al*. 1980). The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a five-point scale. Response options range from 0 (Never) to 4 (Nearly Always). A higher score indicates an increased burden.
- Locus of control (Brown): The Brown Locus of Control Scale (BLOCS; Brown & Granick, 1983) yields three subscales: Internal, External Social and External Other. The questionnaire consists of a total of 25 items. Each item of the BLOCS is rated on a Likert scale from 1 to 6 (1 = ‘strongly disagree’, 6 = ‘strongly agree’).
- HDRS: It is a multiple-item questionnaire used to provide an indication of depression, and as a guide to evaluate recovery (Hamilton, 1960) The questionnaire is designed for adults and is used to rate the severity of their depression by probing mood, feelings of guilt, suicide ideation, insomnia, agitation or retardation, anxiety, weight loss and somatic symptoms. The scale that we used is the version with the 17 items. A score of 0–7 is considered to be within the normal range.

Ethics

The study was reviewed and approved by the Research Ethics Committee at Sligo University Hospital.

Statistical analysis

IBM SPSS Statistics Version 22 was used to perform the statistical analysis of the data. Continuous variables are summarised as means and standard deviations while categorical variables as proportions and percentages. Linear regression analysis with the backward method was carried out to find the independent risk factors of carer burden.

Results

Description of the sample

The sample included 53 carers, 43 (81.1%) female and 10 (18.9%) male, age range 32–81 years. The corresponding 53 patients consisted of 21 (39.6%) females and 32 (60.4%) males, age range 17–92 years (Table 1). The mean time since the patient was diagnosed was 10.87 years (S.D.: 12.58), median 5 years and the range from 1 to 52.

Using the HDRS as dichotomous with cut-off point eight and above, 25 (47.2%) of the carers were diagnosed with depression. Regarding locus of control (BLOCS), 37 (69.8%) of the carers were identified as Internal, nine (17%) as External Social and seven (13.2%) as External Other. In Table 2 the means and standard deviations of the continuous variables that have been measured are presented.

Linear regression analysis with the backward method was carried out to find the associated factors of carer burden. The initial model had ZBI scores as the dependent variable and the following as independent variables: age of carer, sex of carer, marital status of

Table 1. *Carer and corresponding patient demographic characteristics and main diagnoses*

	Carer (n = 53)	Patient (n = 53)
Age (mean ± SD)		
Gender [n (%)]	64.5 ± 11.7	72.1 ± 15.6
Male	10 (18.9)	32 (60.4)
Female	43 (81.1)	21 (39.6)
Marital status [n (%)]		
Married	41 (77.4)	34 (64.2)
Single	7 (13.2)	8 (15.1)
Separated	1 (1.9)	11 (20.8)
Widowed	2 (3.8)	0
Divorced	2 (3.8)	0
Relationship to patient: [n (%)]		
Spouse	30 (56.6)	
Parent	4 (7.5)	
Child	17 (32.1)	
Other	2 (3.8)	
Diagnosis of patient requiring care [n (%)]		
Dementia	26 (49.1)	
Chronic mental illness	18 (34.0)	
Neurological disease	5 (9.4)	
Developmental/other	4 (7.5)	

Table 2. *Means and standard deviations of continuous measurements*

	n	Mean	S.D.
Zarit Burden Interview	53	33.01	17.91
Neuropsychiatric Inventory	53	13.50	11.09
General Health Questionnaire	53	24.78	6.82
The Social Network Index			
(a) Network diversity	53	5.95	1.80
(b) Number of people in social network	53	25.56	23.44
(c) Number of embedded networks	53	2.19	1.31
Short Form Survey			
Physical functioning T-score	53	46.44	11.25
Role limitation physical T-score	53	25.79	4.21
Pain T-score	53	45.73	14.09
General health T-score	53	42.94	11.14
Vitality T-score	53	45.82	15.08
Role limitation emotional T-score	53	18.52	4.51
Social functioning T-score	53	52.49	16.93
Mental health T-score	53	49.76	13.85
Physical health composite T-scores	53	44.31	9.64
Mental health composite T-scores	53	40.52	10.95

carer, relation of carer–patient, receiving respite previously, major diagnosis of patient, years of illness of patient, patient NPI score, BLOCS, SNI, HDRS and the eight domains of SF-12 scale. The GHQ-12 was not included in this model because it had high correlation with the mental health scores of SF-12 ($r = -0.56$, $p < 0.0001$) and HDRS ($r = 0.321$, $p = 0.029$). The final model is presented in Table 3. The data were screened for multicollinearity and the standardised residuals for normal distribution. No violations of the assumptions for linear regression were found (tolerance <1 and variance inflation factor <10.0).

As it can be seen from Table 3 significant risk factors for carer burden are patients' behavioural problems as indicated by the NPI, younger age of the carer, female carer, unmarried or divorced carer, small number of fixed networks but high number of people in social networks, lower physical functioning and limitation of role due to emotional problems. Insignificant factors excluded from the model were the diagnosis of patient ($p > 0.05$), years of illness of patient ($p > 0.05$), locus of control ($p > 0.05$), presence or not of depression in the carer, and previous use or not of respite care ($p > 0.05$).

Discussion

Patients' characteristics

The results suggest that only one patient characteristic – behavioural problems was a significant factor for carer burden, the rest were individual personal and social characteristics of the carer.

The finding of this study that behavioural disturbances are a risk factor for carer burden is in line with previous research (Donaldson *et al.* 1998; Donaldson & Burns, 1999). In a meta-analysis (Black & Almeida, 2004) but only in patients with dementia further supported the notion that patients' behavioural problems is a predictor of burden of carer. More recent research and meta-analyses (Ornstein & Gaugler, 2012; Prince *et al.* 2012; Sutcliffe *et al.* 2015) also confirm those findings. Prince *et al.* also reported that ZBI increased by approximately one point for every one point increase in NPI severity. In concordance with other studies (e.g. Dauphinot *et al.* 2015) diagnosis and years of illness were not significant factors for carer burden.

Carers' demographic characteristics

Similarly, female gender is often reported as a significant risk factor for carer burden (Donaldson & Burns, 1999; Sutcliffe *et al.* 2015) not only in patients with dementia but as well as in patients with other chronic illness or terminally ill (e.g. Schrank *et al.* 2016). A number of explanations of this consistent finding have been suggested among them that females carers assume that care is their obligation (García-Calvente *et al.* 2004), and thus they ask less often for help (Casado-Mejía & Ruiz-Arias, 2016), that there is an influence of social roles and

Table 3. *Independent factors that predict carer burden as measured with the Zarit Burden Interview (ZBI)*

	Unstandardised coefficients		Standardised coefficients			Collinearity statistics	
	B	S.E.	β	*t*	Significance	Tolerance	VIF
Constant	64.69	18.09		3.57	0.001		
Age of carer	−.341	0.14	−0.23	−2.29	0.026	0.83	1.20
Gender of carer	14.96	4.29	0.34	3.48	0.001	0.86	1.16
Marital status of carer	3.74	1.81	0.21	2.06	0.045	0.76	1.30
NPI	0.23	0.07	0.32	3.13	0.003	0.79	1.26
Number of people in social network (SNI)	0.25	0.11	0.32	2.28	0.027	0.43	2.29
Number of embedded networks (SNI)	−4.95	2.01	−0.34	−2.45	0.018	0.43	2.28
Physical functioning (SF-12)	−.40	0.17	−0.25	−2.27	0.028	0.70	1.42
Role limitation emotional (SF-12)	−1.44	0.44	−0.35	−3.27	0.002	0.72	1.38

VIF, variance inflation factor; NPI, Neuropsychiatric Inventory; SNI, Social Network Index; SF-12, Short Form Survey. The sign (+ or −) in the second and fourth column implies the direction of the relationship between the variable and ZBI scores. For example, younger age of the carer is associated with higher scores in ZBI (higher burden) at a significance level of $p = 0.03$.

cultural factors (Ingersoll-Dayton, 2011) which protect male compared to female carers. Females are involved more emotionally in care tasks, use more emotion-focussed styles when facing stress, perform more intense and complex tasks, while males protect their personal space, use more problem-focussed coping styles, do mainly instrumental tasks, have less emotional involvement and ask for help more easily (Garity, 1997; Ducharme *et al.* 2006; Robinson, 2014; Casado-Mejía & Ruiz-Arias, 2016). In the same line previous research has also reported that marriage is a protective factor for carer burden (Prince *et al.* 2012; Casado-Mejía & Ruiz-Arias, 2016; Nagata *et al.* 2016); however, not many studies have explored this further to identify the reasons.

In addition, our predictive model shows an association of younger age and increased carer burden. Previous studies have shown inconclusive results. For instance, Liang *et al.* (2016) and Rinaldi *et al.* (2005) reported that increased age was a higher risk factor for depression and anxiety in carers, while others (e.g. Cooper *et al.* 2006, 2007) reported no association. However, the above studies have investigated depression and anxiety while studies which investigate only the burden or strain on carers found similar results with the present study (Casado-Mejía & Ruiz-Arias, 2016; Sousa *et al.* 2016). This finding might be because younger carers have also other responsibilities like work or family commitments, the 'sandwich' generation caught between childcare and 'parent' care, and thus they are more susceptible to burden (Ben-Galim & Silim, 2013).

Carers' social networks

Another finding from this study was that the higher the number of embedded networks has a protective effect but conversely, the higher the number of people with whom the carer has regular contact increases the burden. A number of previous studies have also pointed out that stable networks are a protective factor (Wilks & Croom, 2008; Dias *et al.* 2015). However, high number of social contacts has been shown to have a negative effect on mental health not only in caregivers (e.g. Wilks & Croom, 2008) but also in other stressful situations like disasters (Solomon & Smith, 1994). The presence of moderate levels of social support perhaps relieves the burden by emotional support which has been shown to be an important moderator to stress. In contrast, high numbers of social contacts could also pose burden as social networks demand time, responsibilities and can potentially increase stress. Embedded networks represent more structural aspects of social networks and represents the network of people who might provide or did provide these supportive acts.

Carers' personal factors

Two more factors were found to increase the carer burden in the above results, lower physical functioning and role limitation due to emotional problems. Although nearly half of the examined sample was identified as having depression, depression was not a risk factor. This finding might be because 'emotional problems' is a wider concept than depression and thus this variable had a stronger effect in the model compared to depression. Previous research also is in line with this finding (Chumbler *et al.* 2003; Di Mattei *et al.* 2008). However, it also has been reported that levels of emotional distress reach a plateau and remain stable or even improve as caregiving continues but physical problems continue to accumulate during caregiving (Pavalko & Woodbury, 2000).

Limitations

The first limitation of our study is that the cross-sectional design limits any conclusions in a causal direction. Those relationships need to be examined longitudinally to conclude any direction of cause-effect. However, predictive factors to have meaning and utility need to be identified in a single assessment.

A second limitation of our study is the biased sample. We interviewed only carers who have been referred or self-referred to the Carers Association (Now Family Carers Ireland) and thus our predictive model is limited only to those. Despite this, from our results and in comparison with previous studies it seems that those factors which we identified as risk factors are universal.

Perhaps it could be argued that a limitation of this study is the sample size, however, the sample size was enough to allow calculations and extraction of the model as the number of subjects was more than two per variable as recommended (Austin & Steyerberg, 2015).

One further limitation was the time spent in the caring role. As we did not collect data related to the years of caring but only the years since the first diagnosis, the authors may have overestimated them. However, the years since the diagnosis were not found to be a significant predictor for carer burden.

Conclusions

This study shows that the presence of behavioural disturbances in the patient, and carer variables including female gender, younger age, and unmarried together with emotional and physical functioning limitations as well as having a small number of embedded social networks and high numbers of contacts are risk factors for a higher burden of care. The ability to predict which carers are more susceptible to burden allows physicians to more quickly to identify ‘higher risk’ carers more quickly, facilitating routine check-ups by physicians and carer support services.

Other predictive models in the literature are often confined to specific conditions. For example, in a paper published in the nursing literature (Kim *et al*. 2012) the authors use a hierarchal multiple regression analysis to identify at risk carer groups. Impaired function in care recipients as well as carer factors were all predictors of burden. In a study looking at burden amongst carers of stroke patients a predictive model based on multiple regression analysis was carried out showing that burden was related to age, sex, chronic illness, use of respite care, caregiving hours and care-recipient functional status (Morimoto *et al*. 2003).

A strength of our paper is that it seeks to explore carer burden amongst a more heterogenous population of carers who are availing of a local carer support service. Novel social factors have been identified in the analysis.

Before the authors’ predictive model can be implemented the authors feel that it needs to be further tested in a new prospective study. Other areas of future research that the authors feel is warranted is an investigation of the use of respite care as an alleviator of carer burden.

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Conflicts of Interest

None.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. The authors assert that ethical approval for publication of this audit has been provided by their local Research Ethics Committee.

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