



An evaluation of health and well-being checks for unpaid carers

Angela Burrows
Redbridge Primary Care Trust, Redbridge, UK, and
Kenneth Gannon
University of East London, London, UK

Abstract

Purpose – The purpose of this study is to evaluate the efficacy of providing health and well-being checks and six months support to unpaid carers. Changes in carer stress will be measured between baseline and final assessment.

Design/methodology/approach – This is a cross-sectional, correlational study of the 394 carers recruited and the sub-group of 348 carers who received support for six months. A T-test measured change in the carers' GHQ-12 scores between baseline and final assessment. A chi-squared test was used to measure movement in the GHQ-12 scoring quartiles between baseline and final assessment.

Findings – The 348 carers receiving support for six months reported a statistically significant small reduction in their baseline and final assessment scores. The carers identified by the GHQ as having less severe stress scores did better than those with more severe stress levels.

Research limitations/implications – As there was no control group, it was not possible to compare the outcomes of the intervention group with the outcomes of a group of carers receiving care as usual. It is therefore possible that there may be some other factors at play for the intervention group over the six-month period of support, other than the intervention itself, which have influenced the change in carer stress.

Social implications – Financial pressures on health and social care budgets can lead to carers' support services being under-resourced in some areas. However, the draft Care and Support Bill (July 2012) and the introduction of new mandatory duties may help to ensure that local authorities and health and well-being boards meet their obligations to provide services for carers.

Originality/value – There is limited research available on the outcomes of carers' interventions, particularly those which involve holistic interventions, such as health and well-being checks being delivered by a multi-agency partnership.

Keywords Health checks, Unpaid carers, Evaluation, Personal health, Carers

Paper type Research paper

Introduction

“A carer is defined as someone who, without payment, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability” (Carers Trust, 2012).

One in eight of the adult population of the UK is a carer (Carers UK, 2012). Carers are twice as likely to suffer from ill health as the general population (Department of Health (DH), 2008). Research into carer health has found that the caring role can lead to



emotional, physical and psychological problems, including anxiety and depression (Whitney *et al.*, 2007; Liffé *et al.*, 2002; Mannion, 2008; Schulz *et al.*, 1990). Carers neglect their own health needs due to a lack of time and energy and are less likely to seek medical attention for preventative health concerns (Carers UK, 2004). Carers who provide care for a long period of time are at particular risk of their health suffering (Carers UK, 2004). In particular, carers who provide care for 50 hours a week or more are especially likely to suffer from both physical and mental strain due to the demanding nature of the carer role (Carers UK, 2004).

The findings of a questionnaire-based study of carers of people over 75 years of age indicated that most carer support interventions cater for the physical dimensions of caregiving, but do not address the emotional aspects (Jarvis *et al.*, 2006). The study also found that health and social care professionals have a tendency to focus on supporting the carer to access the services available, rather than providing the emotional support that the carer might need. One of the study's conclusions was that some of the difficulties around caregiving for carers may be the emotional consequences and the impact on family relationships of caring, rather than the practical tasks involved. In common with other studies of the carer experience, the results suggest that carers themselves have high levels of needs that are not usually addressed in clinical practice (Simon *et al.*, 2008; Graap *et al.*, 2008).

The Department of Health (DH) White Paper Department of Health (DH) (2006) stressed the importance of addressing carers' needs in the health system (Yeandle and Wigfield, 2011). The Carers' Strategies developed by the DH recognize that the physical health needs and the well-being and mental and emotional health needs of carers need to be supported (Department of Health (DH), 2008, 2010). The central role of unpaid carers in continuing to provide support to those they care for has increasingly been recognized in monetary value as cost saving for the tax payer – £87 billion per year, or equivalent to the cost of the NHS (Buckler and Yeandle, 2007). In 2007, the Prime Minister at the time announced a New Deal for Carers (Yeandle and Wigfield, 2011). This included funding planned short breaks for carers and recognition of the need to provide more personalized and integrated support to carers across the health and social care system. More recently, the draft Care and Support Bill, July 2012, is intended to impose a number of new or enhanced mandatory duties of direct benefit for carers. Clause one is the duty to promote individual well-being. This recognizes that well-being encompasses the physical and mental and emotional state of an individual. Clause seven places a duty on local authorities to provide or arrange for the provision of preventative services and identify those adults whose needs are not being met, clause ten places a new duty on local authorities to provide carer's assessments based on "appearance of need" rather than the carer being required to request an assessment, or the carer providing substantial care, both of which are currently the case (Carers UK, 2012).

In 2009 the DH funded sites to study the impact and effectiveness of new and innovative ways of supporting carers, as there was inadequate research available in the area (Yeandle and Wigfield, 2011). Redbridge, an outer north-east London (ONEL) borough with a population of 274,000 and approximately 27,000 carers (Office of National Statistics, 2001), was selected as one of these sites. The site's specific focus was to deliver a health and well-being check and provide six months support to carers of patients at risk of admission to hospital. It was perceived that this group of carers would potentially have the highest stress levels.

A holistic health and well-being check was devised so that it would address both the physical health and emotional and well-being needs of the carer. The site adopted

the principles around self-care and self-management through integrating a personal action planning approach into the health and well-being check. This approach involved the community nurses working with the carer support workers and the carers to identify how the carer's health and well-being might be improved. Emotional support around carer-related issues, advice on how to access services and onward referrals to appropriate services were a key element of the check, along with the delivery of interim reviews at 12 weeks and exit reviews at 26 weeks. The decision to provide support for six months was based on the need to ensure that the outcomes of onward referrals and interventions were known, and that sufficient numbers of carers were able to benefit from the pilot's finite resources. Due to pressures on the central DH budget, the delivery period for all pilot sites was shortened from 24 months to 18 months (Yeandle and Wigfield, 2011).

The bid for the pilot had focussed on recruiting and delivering the health and well-being check to 394 carers, providing ongoing support and measuring the impact of the intervention for a sub-group of 348 carers at 26 weeks. Due to constraints around the available resources to support carers in the borough and the adverse publicity surrounding this, the steering group decided not to exclude any carers resident in the borough wishing to benefit from the intervention. It was recognized that the absence of a control group for comparative purposes would restrict the interpretation of the value of the intervention. However, it was also perceived that there would be significant value in understanding whether the carer cohort perceived that there had been any change in their stress levels, as measured by any change in their general health questionnaire (GHQ)-12 score from baseline to final assessment. The main hypothesis examined by this study was therefore to understand if the delivery of a health and well-being check and the provision of carer support for six months had resulted in a reduction in carer stress and strain for the intervention group.

Study design and methodology

The study was a cross-sectional, correlational study. In order to evaluate the impact of delivering the intervention and measure any reductions in stress, the GHQ-12 was used to record the well-being of the carer before and six months after the check. The GHQ-12 was selected as the most appropriate tool for evaluating carer stress (Campbell *et al.*, 2003; Blake and Lincoln, 2000), because of its reliability (Hankins, 2008) and its ability to be understood and completed in less than 5 minutes (Goldberg and Williams, 1988). This was considered to be a key priority for carers in terms of limiting the number of potential off-putting factors around being involved in a research study (Carers Advisory Group, 2010). Studies have established the content validity of the GHQ-12 and have demonstrated that it has good test-retest reliability (Goldberg and Williams, 1988).

The GHQ-12 has 12 questions, each with four possible responses. The Likert scoring option was used in which the response options are scored from 0 to 3, so the minimum overall score is 0 and the maximum overall score is 36. Higher scores are indicative of psychiatric disorder and in many studies a score of over 18 is considered to be indicative of psychiatric caseness (Goldberg and Williams, 1988). Examples of questions used by the GHQ-12 (Goldberg and Williams, 1988) are:

- Have you recently felt constantly under strain?
- Have you recently lost much sleep over worry?

An exit questionnaire was also devised by the Carers' Working Group and piloted with a small number of carers. The objective of the questionnaire was to

enable the carers to evaluate their outcomes. Examples of questions used by the questionnaire are:

- During the last six months, have you visited your GP for a follow up appointment as a result of having a health and well-being check?
- If you have visited your GP as a result of having a health and well-being check, have you been referred by your GP for any follow up checks?
- If you feel that there have been changes for the better for you in the last six months, do you feel that any of these changes have been because of the health and well-being checks for carers pilot?

Methods

In March 2010 the ONEL Research Ethics Committee (REC) approved the study and verbal and written consent was obtained from the carers recruited. Carers were referred by general practitioners (GPs), and health and social care professionals from the statutory and voluntary sectors. Carers were registered with Redbridge GPs and providing substantial and regular care for a friend, neighbour, partner, spouse, sibling or child. A local media campaign was run, which generated a substantial number of self-referrals. The study focusses on the 394 carers recruited and the sub-group of 348 carers who remained in receipt of support and were followed up at 26 weeks. The potential efficacy of the intervention was identified through measuring differences between individual carers' GHQ-12 scores on entry and exit from the study, i.e. at 0 and 26 weeks.

Following recruitment to the study, a clinical health check was completed by one of the community nurses in the pilot delivery team at the first appointment with the carer. The GHQ-12 was posted to the carer before the appointment and completed by the carer either prior to or during the appointment. Carers also received a well-being assessment from one of the carer support workers in the pilot delivery team, either during the first appointment or at a subsequent appointment. Carers were provided with informal emotional support once on caseload, and advice and information about the carers' services available in the borough, and onward referral to services if appropriate. They also received a 12-week and 26-week exit review. The final assessment GHQ-12 and exit questionnaire was posted out to carers before their 26-week review and collected by the well-being workers at the review. The data sets were entered into SPSS-18 for analysis. Two carers were removed from the sample due to incomplete GHQ-12 scores, reducing the total number of carers on entry to 394. A *t*-test measured mean change in the carers' GHQ-12 scores between baseline and final assessment. A χ^2 -test measured the movement on entry and exit between the numbers of carers in scoring quartile ranges from 0-17, 18-23, 24-29 and 30-36.

Findings

Participants

Of the 394 carers recruited, 87 per cent ($n = 341$) self-referred. 70.3 per cent were female ($n = 277$), 46 per cent ($n = 181$) were over 65 years old, 91.8 per cent ($n = 362$) were co-residing and 16 per cent ($n = 63$) were working. The largest ethnic groupings were: British (white) 43 per cent ($n = 176$), Indian (Asian or Asian British) 30 per cent ($n = 108$) and black (both Caribbean and African) 6 per cent ($n = 19$). The ethnicity and health condition profiles were representative of a similarly aged cohort of residents for

the borough with or without caring responsibilities, with 80 per cent ($n = 316$) of the carers having diagnosed conditions (Redbridge Public Health Report, 2010).

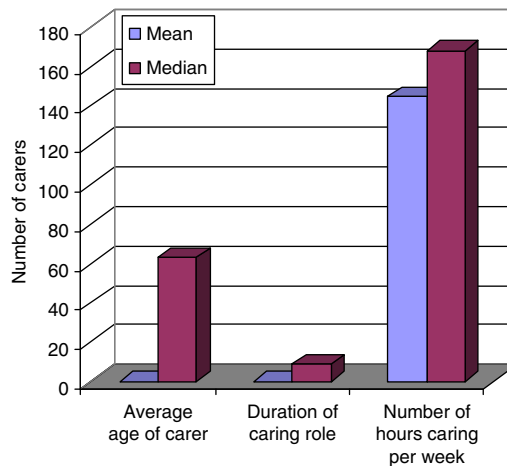
In total, 36 per cent of carers ($n = 152$) thought that they had experienced changes for the better as a result of being on the pilot. In all, 30 per cent of the carers ($n = 120$) had visited their GP as a result of having a health and well-being check. Of the 50 carers who were referred onwards, 26 per cent were referred to the hospital for further tests, 13 per cent were referred to outpatients' clinics and 11 per cent were referred for screening. 4 per cent of carers were referred for a Carer's Assessment. In total, 13 carers reported that they had received a diagnosis of a new health condition and one carer had a care package agreed.

Measures of central tendency showed that the mode for carer age was 56 years old, that carers had been caring for ten years or more and for 168 hours a week, with a mean of over 144 hours of care being provided a week. The carer cohort was on the "heavy" duty end of the carer typology with 82 per cent of the cohort providing care for 50 hours or more and only 18 per cent providing care for less than 50 hours. This compares with 20 per cent of Redbridge carers providing more than 50 hours care a week (Redbridge Carers Strategy 2008-2011, 2008). The sample of carers were therefore providing both a higher number of hours, and a higher intensity of caring than the broader carer population. We know that carers who provide care for 50 hours a week or more are particularly likely to suffer from both physical and mental strain due to the demanding nature of the carer role (Carers UK, 2004).

Figure 1 summarizes information relating to the characteristics of the carers' roles.

Analysis of the carer cohort completing the intervention (n = 348)

In this study 18 was the threshold for mental health issues within the scoring methodology used in this study (Goldberg and Williams, 1988), so at 15.51 the average score on entry is quite high (SD 6.07). The mean on exit was 13.81 (SD 5.94). The difference of 1.7 points (SD 5.48, lower CI 1.13, upper CI 2.28) in the one-tailed t -test was found to be statistically significant $t = 5.80, p = < 0.001$. The effect size of 0.28 was determined by calculating the difference in the means on entry and exit (1.7) and dividing this by the pooled standard deviation of 6.01. According to Cohen's criteria



Note: $n = 394$

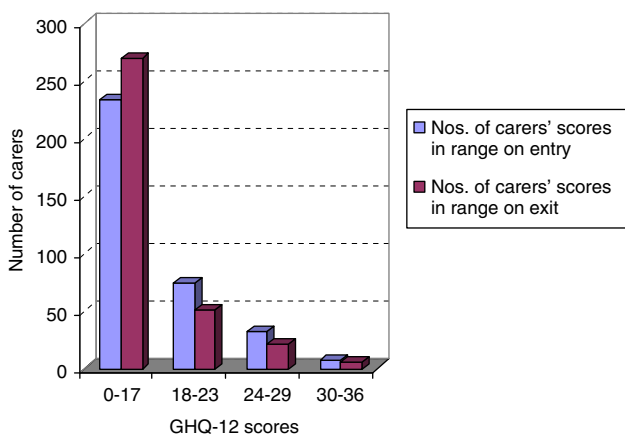
Figure 1.
Average age of carer, duration of caring role in years, hours of caring per week

(Cohen, 1988) the effect size is small. To identify whether the intervention might have had more impact on carers with higher or lower GHQ scores on entry to the pilot, those who received support were split into four groups. The first group was carers scoring between 0 and 17 on entry to the pilot, while carers with scores above the threshold for caseness were split into three quartiles 18-23, 24-29 and 30-36. Across the carer cohort there was an increase in the numbers of carers reporting lower scores across the quartiles, as shown in Figure 2. There was also a significant increase in the number of people scoring below the criterion for caseness following the intervention ($\chi^2 = 76.23$, $df (9)$, $p \leq 0.01$).

Discussion and implications for implementation and for carers

The hypothesis was that the delivery of a health and well-being check and the provision of carer support for six months would result in a reduction in carer stress and strain. There was a small but statistically significant reduction in the mean GHQ scores for the cohort of carers completing the pilot. However, as there was no control group it is not possible to compare these outcomes with the outcomes of a group of carers receiving care as usual. It is therefore possible that there may be some other factors at play for the intervention group over the six-month period of support, other than the intervention itself, which have influenced the change in carer stress. The interpretation of the value of the intervention is therefore restricted by this research limitation. However, a large number of carers reported that they had experienced changes for the better as a result of being on the pilot. A significant percentage of carers also reported visiting their GP as a result of having the health and well-being check.

At 15.5 the average entry score on the GHQ is close to 18, the threshold for mental health issues within the scoring methodology used in this study (Goldberg and Williams, 1998). On entry to the pilot 29 per cent of the cohort had scores of 18 or higher. On exit from the study, 22 per cent of carers remained above the threshold for mental health issues. The carers identified by the GHQ as having less severe stress scores did better than those with more severe stress levels. This potentially suggests that the intervention could have been less efficacious in reducing stress in carers with higher stress levels.



Note: $n = 348$

Figure 2.
 χ^2 – the movement between GHQ-12 scoring quartiles from baseline to final assessment for carers receiving 26 weeks support

However, it might also substantiate a broader finding around the efficacy of the intervention in terms of a carer typology.

Previous studies of carer support interventions have shown that carer interventions cater for the physical dimensions of caregiving, but that the emotional support that carers need can get overlooked by health and social care professionals (Jarvis *et al.*, 2006). The small effect size might suggest that a more intensive intervention might be required to deliver reductions in stress levels for carers with heavy duty caring responsibilities.

The integrated nature of the intervention and the concept of personal action planning was reported on favourably by the Carers' Working Group involved in the service evaluation (Burrows *et al.*, 2011). The delivery team comprised community nurses and carer support workers. The team asserted that they had increased their knowledge of carers' services in the borough, and how to make onward referrals (Burrows *et al.*, 2011). The benefits of partners gaining increased understanding of different ways of working and organizational cultures was also reported by lead professionals in the delivery organizations (Burrows *et al.*, 2011). Amongst the partner commissioner and delivery organizations, the pilot was perceived to have been a success, with measurable outcomes for the carers and the agencies involved. Whilst the shift in the financial climate appears to have resulted in the prioritization of NHS resources on the delivery of the quality, innovation, prevention and productivity (QIPP) agenda, Redbridge has sought to maintain its focus on joint working. Redbridge has introduced integrated case management teams, in which health and social care colleagues work together to complete one assessment of an individual's needs and devise a joint plan to address the individual's needs. Section 256 monies have been invested in this new type of service provision.

The challenge for the NHS and for social care will be to continue to ensure that sufficient resources are targeted on early intervention and prevention measures which will assist in reducing costs further downstream in the health and social care systems (DH, 2008). The draft care and support bill recognizes that the "well-being" of a carer includes a carer's physical, mental and emotional health, it also places duties on local authorities to provide or arrange for the provision of preventative services and ensures that all carers will receive an assessment based on the "appearance of need". The Health and Well-being Boards with the focus on progressing integrated working opportunities between health and social care organizations, provide a key opportunity for carers' needs to be considered in the round.

It would appear that central government has accepted that carers' support services are now essential to maintaining health and well-being, but the challenge locally will be to make the case for investment in early intervention and prevention services for carers. Inevitably the measurement of the value of a break or a health check may be challenging, as it can be difficult to effectively isolate and measure the impact of an intervention which can act as a "gateway" and lead to carers' accessing other services as a result. However, the cost of not providing adequate support for carers earlier on in the carer's career is likely to lead to increased costs for the health and social care system when the carer's health breaks down and their cared for is admitted to hospital or to residential care (Yeandle and Wigfield, 2011).

Whilst the DH publicly announced increased investment in PCTs' and Clinical Commissioning Groups (CCGs) allocations for carers' breaks until 2015, the allocation has not been ringfenced in baseline budgets, which has allowed for PCTs with cost pressures to utilize the funding for growth in demand in other areas, such as the costs

of acute care (Carers Trust, 2012). If the DH were to support the funding of a large scale randomized control trial (RCT) for carers' breaks and other types of carer support in which carers were randomized to intervention and care as usual groups, then the evidence base for supporting carers could be fully considered and evaluated by commissioners. It remains to be seen whether the abolition of PCTs with effect from 1 April 2013 and the introduction of CCGs will present the requisite opportunity for the NHS to work more collaboratively with social care partners to deliver the carers' support services required locally.

References

- Blake, H. and Lincoln, N.B. (2000), "Factors associated with strain in co-resident spouses of patients following stroke", *Clinical Rehabilitation*, Vol. 14 No. 3, pp. 307-314.
- Buckler, L. and Yeandle, S. (2007), *Valuing Carers – Calculating the Value of Unpaid Care*, Carers UK, University of Leeds, September.
- Burrows, A., Matthews, A., Wan, A. and Saleh-Jahromi, K. (2011), "An evaluation of the health and well-being checks for carers pilot in Redbridge", NHS Redbridge and London Borough of Redbridge, Redbridge, July.
- Campbell, A., Walker, J. and Farrell, G. (2003), "Confirmatory factor analysis of the GHQ-12: can I see that again?", *Australian and New Zealand Journal of Psychiatry*, Vol. 37 No. 4, pp. 475-483.
- Carers Advisory Group (2010), Minutes, working group, NHS Redbridge and London Borough of Redbridge, Redbridge, December.
- Carers Trust (2012), "Carers breaks on the brink?", briefing paper, Carers Trust, London, December.
- Carers UK (2004), "In poor health – the impact of caring on health", policy briefing, London, Carers UK, December.
- Carers UK (2012), "Draft care and support bill", policy briefing, Carers UK, London, July.
- Cohen, J. (1988), *Statistical Power Analysis for the Behavioral Sciences*, 2nd ed., Lawrence Earlbaum Associates, Hillsdale, MI.
- Department of Health (DH) (2006), *Our Health, Our Care, Our Say: A New Direction for Community Services: A Brief Guide*, Department of Health, London.
- Department of Health (DH) (2008), *Carers at the Heart of 21st Century Families and Communities*, Department of Health, London.
- Department of Health (DH) (2010), *Recognised, Valued and Supported: Next Steps for the Carer's Strategy*, Department of Health, London.
- Goldberg, D. and Williams, P. (1988), *A User's Guide to the General Health Questionnaire*, GL Assessment, London.
- Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J. and De Zwaan, M. (2008), "The needs of carers of patients with anorexia and bulimia nervosa", *European Eating Disorders Reviews*, Vol. 16 No. 1, pp. 21-29.
- Hankins, M. (2008), "The reliability of the twelve-item general health questionnaire (GHQ-12) under realistic assumptions", *BMC Public Health*, Vol. 8 No. 335, pp. 1471-2458.
- Jarvis, A., Worth, A. and Porter, M. (2006), "The experience of caring for someone over 75 years of age: results from a Scottish general practice population", *Journal of Clinical Nursing*, Vol. 15 No. 13, pp. 1450-1459.
- Lliffe, S., Wilcock, J., Austin, T., Walters, K., Rait, G., Turner, S., Bryans, M. and Downs, M. (2002), "Dementia diagnosis and management in primary care", *Dementia*, Vol. 1 No. 1, pp. 11-23.

-
- Mannion, E. (2008), "Alzheimer's disease: the psychological and physical effects of the caregiver's role. Part one", *Nursing Older People*, Vol. 20 No. 4, pp. 27-33.
- Office of National Statistics (2001), *2001 Census Analysis: Unpaid Care in England and Wales*, Office of National Statistics, New Port.
- Redbridge Carers Strategy 2008-2011 (2008), NHS Redbridge and London Borough of Redbridge, Redbridge, July.
- Redbridge Public Health Report (2010), NHS Redbridge, Redbridge, March.
- Schulz, R., Visintainer, P. and Williamson, G.M. (1990), "Psychiatric and physical morbidity effects of caregiving", *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, Vol. 45 No. 5, pp. 181-191.
- Simon, C., Kumar, S. and Kendrick, T. (2008), "Formal support of stroke survivors and their informal carers in the community: a cohort study", *Health & Social Care in the Community*, Vol. 16 No. 6, pp. 582-592.
- Whitney, J., Haigh, R., Weinman, J. and Treasure, J. (2007), "Caring for people with eating disorders: factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders", *British Journal of Clinical Psychology*, Vol. 46 No. 4, pp. 413-428.
- Yeandle, S. and Wigfield, A. (2011), *New Approaches to Supporting Carers' Health and Well-Being: Evidence from the National Carers' Strategy Demonstrator Sites Programme*, Centre for International Research on Care, Labour and Inequalities, University of Leeds, November.

Further reading

- Carers UK (2010), "Facts about carers", policy briefing, Carers UK, London, December.
- Department of Health Resource Pack (2008), *Making the Strategic Shift Towards Prevention and Early Intervention: Key Messages for Decision Makers*, Department of Health Resource Pack, London.
- Gilhooly, M. (1994), "The impact of caregiving on caregivers: factors associated with the psychological well-being of people supporting a dementing relative in the community", *British Journal of Medical Psychology*, Vol. 57 No. 1, pp. 35-44.
- King's Fund Website (2006), *Combined Predictive Model Final Report and Technical Documentation*, King's Fund Website, London.

Corresponding author

Angela Burrows can be contacted at: angela.burrows2@ntlworld.com