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Measuring Carer Burden in Informal Carers of Patients with Long Term Conditions: A literature review.

Abstract

Introduction: The aim of this literature review is to identify the most common tools used to measure burden in carers of people with Parkinson's Disease (PD), Heart Failure (HF), Multiple Sclerosis (MS) and Chronic Obstructive Pulmonary Disease (COPD). *Method:* Databases such as Medline, PsycINFO, CINAHL and Academic Search Complete were searched. Studies in which carer burden was measured were included. *Results:* Zarit Burden Inventory and Caregiver Reaction Assessment were most commonly used to measure carer burden, regardless of the chronic condition. A wide range of other instruments were also used. *Conclusion:* Even though a range of tools are available, further improvements are necessary in order to enable healthcare professionals to identify carers experiencing high burden.

Key Words: Carer, Burden, Long Term Conditions, Tools, Assessment

Introduction

As a result of people living longer, an increase in morbidity and the restrictions on NHS spending over recent years, fundamental changes in the way healthcare services are delivered have to be made. Improvements in treatments has led to people surviving with long term conditions for longer and as hospital care is considered to be more costly than healthcare provided in community settings, a central aim of the UK government is to provide integrated healthcare services closer to where people live (Coulter at al, 2013). This has the potential to increase the pressures placed on

informal carers supporting those with long term health conditions (Lutomski *et al.,* 2015).

Background

It was estimated that in 2011 there were 6.5 million unpaid carers in England, Scotland and Wales, a number which has significantly increased since 2001 (ONS, 2013). The increase in the number of carers reflects a significant change in socio-demographic trends and the role of unpaid carers (Pickard et al, 2015). Smaller families and more women in full time employment has led to challenges for those expected to perform caring responsibilities (Lutomski *et al.,* 2015).

Unpaid care involves providing support with the activities of daily living and it is mostly an unpaid activity (Baldwin, 2015) provided to a family member, neighbour or friend to someone who has a health problem (Keeley & Clarke, 2003). The physical limitations of those requiring support often increases their reliance on unpaid carers (Humphrey *et al.,* 2013). Similarly, as the cognitive abilities of those requiring support diminish, this will often increase their reliance on relatives or friends (Mosquera *et al.,* 2016). The only exceptions seem to be spouses, who usually do not choose to become a carer but gradually adopt the role as their partners' health declines (Sloan, 2012). Braine and Wray (2016) recognises the normality of adjusting to the role of carer for those over the age of 75 but they recognise that caring is more challenging for younger people who take on the unpaid caring role. Literature suggests that more females than males are carers and in most cases, they do not have any formal training to carry out the role and the range of their responsibilities tends to gradually increase (Erlingsson *et al.,* 2012).

Although it is acknowledged that female carers appear to experience more stress associated with unpaid caring roles than males this appears to be attributed to the more managerial style of caring adopted by men that allows themselves a distance from the strain of caring (Draper 2014). The social responsibility for caring is often shaped by the structures of family life and the expectations that arise from the relationships that exist within the family unit so impacting on how carer burden is experienced (Hincote and Wasserman, 2017). Unpaid caring is considered to be beneficial for the healthcare system as it can prevent hospital admissions for those with long term conditions (Sloan, 2012). It also has what Van Durne et al (2012: p.491) describe as a 'positive cost efficiency' effect on NHS budgets. However, this has also led to unpaid carers having to manage clinically unstable patients, responsible for the administration of medication as well as dealing with complex medical information (Hellesø *et al.,* 2012).

Carer Burden

The impact of informally caring for a person with a long-term condition has been identified as the perceived carer burden (Jenkinson *et al,* 2011) measured using a variety of tools in relation to the physical, psychological, financial and social impact of caring (Brouwer *et al.,* 2006). In a study by Makdessi et al (2011), 44% of carers reported anxiety symptoms and 24% described symptoms associated with depression. Evidence suggests that the higher the level of dependency of a care recipient and the more caring tasks involved, the poorer health outcomes are for the carers (Jenkinson *et al,* 2011). Safavi et al (2017) accepts that those carers with less social support and poor coping mechanisms are at more risk of experiencing depression and anxiety disorders. The general health and mental well being of those caring for someone with heart failure are consistent with those caring for someone

with cancer (Bausewein et al, 2016) and caregivers for those individuals with end stage, Parkinson's disease report high levels of depression and anxiety and low levels of quality of life (Chaudhuri et al, 2014).

Growing demand for unpaid carers means that in the future more individuals will have to combine their careers with caring responsibilities. According to Lilly et al (2007), carers cohabiting with care recipients are more likely than any other carer group to have to stop working altogether. In some cases the impact of carer burden can result in deterioration in the carer's health, and hence why it is so important to recognise, measure and address the impact of providing unpaid care (Grässel *et al.,* 2014). A systematic review by Whalen and Buchholz (2009) examined international quantitative research papers that focused on the psychometric properties and feasibility of caregiver burden screening tools. The review concluded that because caregiver burden is a multidimensional and complex issue, clinicians need to be specific in their choice of the tool for use for assessing carer burden.

Despite the consequences of carer burden, the literature fails in providing a universal definition of how it should be measured (Mosquera *et al.,* 2016). According to Zarit et al (1986: p.260) carer burden can be defined as 'the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning'. Some authors have differentiated between objective and subjective measures of carer burden (Brouwer *et al.,* 2006). Objective burden refers to the type and frequency with which caregiving tasks are performed, whilst subjective burden refers to the cognitive appraisal of caring (Makdessi *et al.,* 2011) or how individual carers perceive the impact of caring on them. There appear to be some inconsistencies in the literature related to the fact that different caring tasks are often included in measuring carer burden, making it difficult to estimate how much

time carers spend performing these duties leading to underestimations of carer burden (McPhee *et al.,* 2010).

Most attempts to measure carer burden, focus on the impact of caring for those with specific health conditions, such as dementia, stroke or mental health problems such as schizophrenia (Viana *et al.,* 2013). According to Glajchen et al (2015), long term caregiving can result in depression, social withdrawal, impaired quality of life or even increased mortality for the carer. Elderly carers are at a particular risk as often they have health problems themselves, although in most cases less severe than care recipients (Mosquera *et al.,* 2016). These individuals have been recognised as 'hidden' carers who are at an increased risk of experiencing carer burden, but they do not recognise themselves as carers because they consider their caring role as a natural consequence of a relationship such as being a spouse (Viana *et al,* 2013).

Several tools used to measure carer burden have been identified including the Zarit Burden Inventory (Zarit *et al.,* 1980) and the Caregiver Reaction Assessment. Other measures include: Caregiver Burden Inventory (CBI), Burden Scale for Family Caregivers (BSFC), Caregiver Reaction Assessment (CRA), Multidimensional Caregiver Strain Inventory (MCSI) and many others (Greenwell *et al.,* 2015). Most of them have only been validated in relation to carers providing support with specific health conditions such as dementia, cancer and mental health conditions (Glajchen *et al.,* 2015) and there appears to be a disagreement in the literature as to whether it is more effective to use disease-specific instruments (Humphrey *et al.,* 2013) or generic tools to screen for and measure carer burden (Deeken *et al.,* 2003).

This review aims to examine the tools used to measure carer burden in those caring for someone with one of four physical, long term health conditions: Parkinson's

Disease (PD), Heart Failure (HF), Multiple Sclerosis (MS) and Chronic Obstructive Pulmonary Disease (COPD). These are four of the most common long term health conditions that are managed and supported by community and primary healthcare services and it is this group of patients who are specifically at risk from repeatedly being admitted to hospital (Chilton et al, 2012). The review also aims to address some of the limitations of the studies identified and to provide some value to the literature on the management of long term conditions in primary and community healthcare services as well as considering the use of a generic screening tool that measures carer burden.

The four conditions listed affect as many as 2 million people in the United Kingdom. Since most of the people diagnosed with them require help from unpaid carers, it is particularly important for this group of carers to be supported by healthcare professionals working in primary and community settings (Whittingham *et al.,* 2013).

Method

This literature review followed the method recommended by Hawker et al (2002). It appraised the evidence from research studies and literature reviews to examine the tools used to measure carer burden in informal carers of patients with Parkinson's Disease; Heart Failure; Multiple Sclerosis; and Chronic Obstructive Pulmonary Disease. The search terms used included: carer, caregiver, impact, burden, measuring, measurement, Parkinson's Disease, PD, Heart Failure, HF, Multiple Sclerosis, MS, Chronic Obstructive Pulmonary Disease, COPD. Terms 'AND' and 'OR' were used to narrow/broaden search results and identify relevant studies. The electronic databases used were CINAHL, MEDLINE, PsycINFO and Academic Search Complete.

Results

Parkinson's Disease

29 articles were identified after the removal of duplicates. 20 were excluded following the analysis of titles and/or abstracts. Seven full texts were analysed (including one systematic review) and one study of carers of people with parkinsonism was also analysed and included in the analysis.

Heart Failure

20 articles were identified after the removal of duplicates. 15 were excluded following the analysis of titles and/or abstracts. Five full texts were analysed, including one study concerning carers of people with MS, which was also found during the further search.

Multiple Sclerosis

23 articles were identified after the removal of duplicates. 17 were excluded following the analysis of titles and/or abstracts. One full text was impossible to obtain, five full texts were analysed, including the article found during the search for articles regarding HF.

Chronic Obstructive Pulmonary Disease

18 articles were identified after the removal of duplicates. 13 were excluded following the analysis of titles and/or abstracts. Only one full text regarding COPD alone was identified, therefore it was decided that four articles regarding multiple conditions (COPD, HF and cancer) would be included in the analysis.

Tools Measuring Carer Burden

Zarit Burden Interview (ZBI)

ZBI is a one dimensional, 22-item instrument. It uses a 5-point Likert scale and it was primarily developed for measuring carer burden in carers of people with dementia. Although shorter versions of ZBI were created, they have not been evaluated and validated as well as the original version (Harkness & Tranmer, 2007). It was the first tool that used self-reports, rather than interviews (Deeken *et al.,* 2003). ZBI was used in eight studies identified in this review, two about PD, four about MS and two about COPD, HF and cancer, although in some of them modifications to the tools were made. Humphrey *et al* (2013) used ZBI to develop the disease-specific instrument as they argued that due to its generic character, it did not have validity among HF carers and did not measure all burden concepts relevant to this disease. In PD studies, carer burden was not associated with the carers' age, however it was found that cognitive symptoms of PD increase burden (Carod-Artal *et al.,* 2013).

ZBI was used in the majority of MS studies and the variety of populations it was applied to further added to its validity. Bayen *et al.* (2015) found that 54% of carers reported perceived burden and the scores were associated with the disability progression and limited cognitive function, which contrasts with the earlier findings of Akkuş and Akdemi (2011). Burden scores in MS were high from the onset of the condition which can be due to the unpredictable nature of the disease (Bayen *et al.,* 2015). The ZBI scores reported by Bayen *et al,* (2015) varied greatly from other studies. The authors suggest that differences might arise from different ways of application of the instrument (questionnaires or interviews) (Rivera-Navarro *et al.,* 2009). Akkuş and Akdemi (2011) argues that higher than in previous studies scores reported in his sample are due to differences in state support available. In studies considering COPD, HF and cancer together, it was found that, as opposed to MS carers, carer burden was not associated

with patients' functional disability (Garlo *et al.,* 2010) and levels of burden were low (Fried *et al.,* 2005).

Caregiver Reaction Assessment (CRA)

CRA is a 24-item measure, which assesses four negative (disrupted schedule, financial problems, lack of family support and health problems) and one positive (carer self-esteem) aspects of caring. Its target population were primarily carers of cancer patients and the elderly (Harkness & Tranmer, 2007) however validating studies on other populations were conducted It is one of the few tools that consider economic burden (Cousins *et al.,* 2002). In this review, the tool was found to be used in studies on carers of people with HF, MS, and COPD, HF and cancer. In their HF sample, Makdessi *et al* (2011) found schedule disruption, health problems resulting from caring, financial problems and family abandonment to be related to the highest burden levels. Similar findings were obtained on a sample of carers of patients with MS (Forbes *et al.,* 2007). They found that negative effects of the disease on QoL were associated with higher levels of burden thus suggesting a relationship between these aspects of caring. Burton *et al* (2012) found no difference in burden levels between carers of people with different conditions. The lack of support was most strongly associated with burden which differs significantly from a HF study reviewed (Makdessi *et al.,* 2011) and later a prospective study of multiple conditions, in which schedule disruption was the most prevalent mediator of burden (Sautter *et al.,* 2014).

Other direct measures of burden

Other direct measures of carer burden used in the reviewed studies include: Caregiver Distress Scale (CDS), Caregiving Distress Scale (CDS^2), Burden Scale for Family Caregivers (BSFC), Multidimensional Carer Burden Inventory (MCBI),

Multidimensional Caregiver Strain Inventory (MCSI), Caregiver Strain Index (CSI), Care-giving Burden Scale (CBS), Caregiver Survey, Burden 2, Impact of Caregiving and Young Carers of Parents Inventory (YCOPI; for adolescents caring for their parents).

Indirect measures

Hospital Anxiety and Depression Scale (HADS), Centre for Epidemiological Studies Depression Scale (CES-D), generic Quality of Life (QoL) measures (EQ-5D, PDQ-8), Perceived Stress Scale (PSS), Short Form General Health Survey (SF-36), Medical Outcome Study Short Form-12 (SF12v1), a psychosocial questionnaire (BELA-A-k). These measures assess physical and/or mental health and in most of the studies included in this review they were used alongside direct measures of burden. Some of the burden measures used were newly designed and in order to validate them, both direct and indirect measures were applied.

Disease-specific measures

Caregiver Burden Questionnaire of Heart Failure (CBQ-HF), Dutch Objective Burden Inventory (DOBI) and Health-Related Quality of Life in Multiple Sclerosis (CareQoL-MS) were instruments designed or modified to measure carer burden in specific populations. BELA-A-k is designed to measure psychosocial problems and need for help in people affected by PD (Spliethoff-Kamminga *et al.,* 2003). It can be applied to both patients and carers and it is a part of PD diagnostic routine in Germany. CBQ-HF investigates physical, psychological, social and lifestyle-related aspects of caring (Humphrey *et al.,* 2013). Although validated only on a specific population, the authors argue that it can be applied to others. DOBI is designed to measure both objective and subjective burden. However, Makdessi *et al,* (2011) reported that the subjective

component was incomplete and could not be used in their analysis as further validation was required. CareQoL-MS is the first tool designed to assess carers of people with MS and its dimensions include: physical burden, social impact, emotional impact, and emotional reactions (Benito-León *et al.,* 2011.

Discussion

This literature review has examined studies examining the tools that measure carer burden in carers of people with four chronic, long term conditions. ZBI and CRA are the most commonly used tools in studies of PD, HF, MS and COPD. However, several indirect measures of carer experience, such as HADS, SF-36, CES-D and others were used alongside the instruments assessing carer burden. This suggests that existing burden measures might not capture all relevant concepts of burden.

Both ZBI and CRA were used in the studies in relation to multiple conditions, which suggest their generic character and is consistent with the systematic review of Greenwell et al (2015). This supports the view that carer experiences are to some extent universal across a range of long term conditions (Burton *et al.,* 2012). It must be noted, that samples in the studies included in the current review were heterogeneous, as care recipients were usually elderly and their conditions were characterised by a long period of decline in their health. The exceptions were studies of MS carers. MS affects younger people, predominantly females and the fact that ZBI and CRA were validated in this populations is to their advantage.

Three disease-specific tools (CareQoL-MS, CBQ-HF and DOBI) were also identified. It can be assumed that the studies considered measures such as ZBI and CRA to be either too generic or to have other disadvantages. Fried et al (2005) argue that the main problem encountered with ZBI is the lack of the guidelines as to how the scores

should be interpreted. As a result, some researchers create their own cut-off points, leading to inconsistencies and misleading conclusions. Some consider disease-specific instruments more effective (Spliethoff-Kamminga *et al.,* 2003) as they consider objective burden to vary between long term conditions (Bayen *et al.,* 2015).

The majority of carers are female (Whittingham *et al.,* 2013; Bayen *et al.,* 2015), but this does not always apply to MS as the disorder affect three times as many women as men (Forbes *et al.,* 2007). The burden levels in MS carers in the studies that used ZBI were higher than in other conditions. In all studies the majority of carers were spouses or patients of care recipients, which is consistent with the literature (Sloan, 2012). They were found to perform more caring activities than any other carer group, which might be due to the fact that they cohabited. This suggests higher objective burden experience, resulting in higher subjective burden (Makdessi *et al.,* 2011; Whittingham *et al.,* 2013). From the studies using CRA, the findings suggest the importance of emotional and social support, consistent with existing literature (Greenwell *et al.,* 2015). Social support was found to be a protective factor and to moderate the demands of caring (Schwarz & Dunphy, 2003).

It needs to be noted that studies included in this review have several limitations. The most common were: small sample size, selection bias and the heterogeneity of samples. Although the tools used had psychometric properties or were in the process of being validated, in some cases insufficiently detailed descriptive statistics were presented. In addition, quantitative measures are largely used to capture caregiver burden, which can be inadequate in identifying certain factors that are important such as culture (Bastawrous, 2013). Only two of the studies adopted a longitudinal design and some studies recognised spouses and partners as one category whilst others did not. This is important as spouses are the group most affected by carer burden

(Makdessi *et al.,* 2011; Whittingham *et al.,* 2013). Self-reports are usually used to measure carer burden, but according to Schwarz & Dunphy (2003), people often tend to avoid reporting negative feelings or do not always realise they are burdened and instead accept it as a moral obligation (Deeken, *et al.,* 2003).

Conclusions

Measuring the effects from providing unpaid care for someone with a long term condition is crucial, as it is increasingly recognised that more healthcare in the future will be delivered away from acute environments (Rahman, 2015). The Five Year Forward View (DH, 2014) highlights the challenges faced by healthcare organisations in the provision of healthcare at or closer to patient's homes resulting in increased pressure on unpaid carers. Therefore, there is a need for community based multi professional healthcare practitioners to utilise a short, generic screening tool to screen for the effects from caring for someone with a long term health condition (Rahman, 2015).

Although existing literature is rich in studies relating to the use of tools to measure carer burden of those caring for people with the most common conditions managed by primary and community healthcare professionals such as PD and HF (Chilton et al, 2012) measuring carer burden associated with MS and COPD appears to be understudied. It has long been recognised that there is a lack of standardization with the tools that exist to measure caregiver burden (Zarit et al, 1980). There is an agreement in the literature that it would be a challenge to develop a generic tool which measures carer burden and one which would consider both objective and subjective reports of burden (Mosquera *et al.,* 2016). However, despite advantages of disease-specific tools, this review has recognised a convincing need for the development of a

short, more generic instrument that could be administered by healthcare practitioners such as nurses or General Practitioners and paramedics to measure the burden of caring for someone with a chronic, long term health condition. The potential impact this will have, specifically for community nurses as those frequently in contact with unpaid carers is that they will be delivering a more carer centred, supportive service in screening for signs of burden and managing them in a timely and effective way.

This review also highlights implications for further research. Due to the lack of a theoretical model of caring (Cousins *et al.,* 2002; Greenwell *et al.,* 2015), existing measures of carer burden are based on theoretical frameworks from other disciplines, such as psychology, psychiatry and sociology even though in practice, nurses are the group which has the most frequent contact with carers. In which case if a carer were to self-assess their level of burden the using a health or professional focussed measure may not be fully appropriate. As such, it may be preferable to have measure that is more person centred and needs based and so a theoretical framework from social care may be the most appropriate. Due to the nature of caring, some can argue that carer-patient dyad should be considered as a whole, rather than as individuals when assessing burden (Forbes *et al.,* 2007). Finally, few studies have considered the positive aspects of caring, such as the satisfaction experienced as part of the carer-recipient relationship, even though they are recognised by the literature (Nolan et al, 1996; Erlingsson *et al.,* 2012; Whittingham *et al.,* 2013).

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