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Burden and unmet needs of caregivers of Chronic Obstructive Pulmonary Disease patients: A systematic review of the volume and focus of research output

Running title: Burden on caregivers of COPD patients

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ABSTRACT

Caregivers of individuals with Chronic Obstructive Pulmonary Disease (COPD) experience significant burden. To develop effective interventions to support this vulnerable group, it is necessary to understand how this burden varies as a function of patient wellbeing, and across the illness trajectory. This systematic review aimed to identify the number and type of databased publications exploring the burden and unmet needs of caregivers of individuals with COPD. Medline, Embase, PsycINFO and Cochrane databases were searched for studies published between Jan 2000 and Feb 2014. Studies were eligible if they were quantitative studies examining unmet needs of, or burden on adult caregivers of individuals with COPD. Eligible papers were categorised according to (i) type (i.e. descriptive, measurement, and intervention studies); (ii) whether they measured associations between patient and caregiver burden; and (iii) whether they measured caregiver burden longitudinally. Twenty-seven databased papers met criteria for inclusion. There was a significant increase in the total number of publications over time. The majority of publications were descriptive studies (n=25), with one measurement and one intervention study identified. Fourteen descriptive studies measured the relationship between patient or caregiver factors and caregiver burden. Only two studies measured caregiver burden over time. There are a number of gaps in the body of research examining burden and unmet needs of caregivers of individuals with COPD that preclude the development of effective interventions for this population. Greater research effort should be directed towards identifying rigorous measurement tools which more accurately characterise caregiver burden, so that evidence-based interventions can be developed.

INTRODUCTION

COPD has a significant burden on both sufferers and their caregivers

Individuals diagnosed with COPD experience physical and psychosocial burdens which negatively impact on their quality of life (1, 2). Debilitating symptoms including dyspnoea, pain and weight loss (3, 4) impose a major physical burden, which can lead to a reduced capacity to carry out activities of daily living (5). A large proportion of individuals with COPD experience psychosocial problems, including anxiety and depression (65%) (6) and social isolation. Patients with late-stage COPD are often confined to their homes, with limited access to and support from community health services (7, 8). Consequently, many individuals with COPD are reliant on informal caregivers to provide in-home care. Informal caregivers of individuals with COPD perform a range of tasks, including medication administration, symptom management and assistance with activities of daily living (9, 10). These responsibilities can take a considerable toll on the physical and mental health of the caregiver. Caregivers of COPD patients report multiple burdens, including fatigue, social isolation, confusion, loss of personal freedom, relationship difficulties, resentment, sleep disturbances, guilt and boredom (3, 11-13). The pervasive burden experienced by these caregivers is compounded by the prolonged trajectory of the disease, underscoring the need for supportive interventions for this vulnerable group.

What do we need to develop appropriate interventions for caregivers of COPD patients?

Developing appropriate interventions to support caregivers of individuals with COPD requires a sufficient understanding of both the time course and antecedents to caregiver

burden. COPD is a progressive illness which can stretch over many years. Therefore it is likely that the type and extent of burden experienced by caregivers would change with the course of the illness. Understanding changes in caregiver burden over time is essential to identifying if there are 'critical periods' during which intervention is most appropriate. To design maximally effective interventions it is also necessary to understand the antecedents which are associated with higher caregiver burden. For example, evidence from other chronic disease populations shows that older caregivers, those who are of lower socioeconomic status, and those with limited social support higher levels of burden (14-17). Patient symptom and psychosocial burden has also been shown to influence the degree of burden experienced by caregivers (18-20). Knowledge of the time course of caregiver burden, and the caregiver and patient characteristics which are associated with greater degrees of caregiver burden will allow interventions to be designed for the most vulnerable groups of caregivers.

Research output as a measure of current knowledge and gaps in research

Examining the volume and scope of research output is one approach to gaining an indication of research capacity and current gaps in the literature. Systematic reviews consistently find a paucity of measurement relative to descriptive research. For instance, assessment of research output related to quality of life for cancer patients (21, 22) identified a lack of research developing or validating tools to assess patient quality of life. This may limit the interpretation of findings from descriptive studies, as outcomes may not be accurately assessed. A paucity of intervention research is also commonly found (21, 23, 24), indicating that knowledge gained from descriptive work may not be translated into interventions designed to improve patient outcomes. Reviews also find that the scope of descriptive research is often limited, with few longitudinal studies conducted relative to cross-sectional

studies (25-27). This limits the value of the information that can be drawn from descriptive studies to inform the development of interventions. There is a need to examine the volume and type of publications investigating burden on caregivers, so that research gaps can be identified.

Aims

To examine the extent to which burden and unmet needs of caregivers of individuals with COPD have been examined in the literature, including the number of:

- 1) publications annually since 2000;
- 2) descriptive, measurement or intervention publications;
- 3) longitudinal compared to cross-sectional studies;
- studies reporting on the caregiver or patient factors which are associated with caregiver burden.

METHODS

Literature Search

Medline, Embase, PsycINFO and Cochrane databases were searched using the Medical Subject Headings (MeSH) and keywords outlined in the Supplementary Material. Search terms related to caregivers and COPD were combined using the Boolean operator AND. Searches were limited to English language studies published with human subjects between January 2000 and February 2014. Reference lists of relevant review articles were also manually searched to identify any other articles that met inclusion criteria.

Inclusion and exclusion criteria

For the purpose of this review, caregivers are defined as "any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health problem" (28). Given the acknowledgement of the role of caregivers in achieving patient-centred care (29), only papers published from 2000 onwards were included to coincide with the release of the Institute of Medicine (IOM) report on patient-centred care (30). Articles were included if they were quantitative studies examining unmet needs of, or burden on adult (over 18 years) caregivers of individuals with COPD. Unmet needs were defined as "issues of concern for which the individual perceives they require assistance" (31). Burden was defined as the presence of physical, psychosocial, emotional and financial problems that may be experienced as a result of caring for the patient (32). Articles that included caregivers of individuals with COPD along with caregivers of individuals with other chronic illnesses were only included if outcomes were reported separately for COPD caregivers. Case studies, commentaries, conference abstracts, protocol papers, editorials and studies not published in English were excluded.

Data coding and extraction

The title and abstract of all retrieved articles were assessed against the eligibility criteria by one author (EM). Two authors (EM and JB) then assessed the full text of the remaining papers against the eligibility criteria. Inter-rater reliability was calculated using Kappa (K). Discrepancies between reviewers were discussed until an agreement was reached. Where agreement could not be reached, a third author (TR) was consulted.

All publications meeting eligibility criteria were first categorised according to whether they used: (a) a *measurement approach* – the development and/or testing of psychometric tools to

assess burden/unmet needs in caregivers of individuals with COPD; (b) a *descriptive approach* – identifying the prevalence or correlates of burden/unmet needs; or (c) an *intervention approach* – testing the effectiveness of an intervention aimed at alleviating burden on caregivers of individuals with COPD. Descriptive studies were categorised according to i) whether they used a cross-sectional or longitudinal design, and ii) whether or not they measured predictors of caregiver burden. Additional study characteristics including the country, study aims and outcomes were extracted by two reviewers. .

Analysis

Poisson regression was used to model trends over time in the numbers of publications examining caregiver burden and unmet needs. Incidence rate ratios with Wald 95% confidence intervals were calculated, with a ratio of 1.00 indicating no change in counts over time. P-values were calculated from the Wald Chi-square.

RESULTS

Search Results

A total of 1,510 citations were retrieved from the searches. After duplicates were removed, 1,071 publications were assessed against the eligibility criteria. Twenty-seven publications were included in the review. Inter-rater agreement between reviewers was high (Kappa = 0.8). A flow chart of the review and exclusion process according to PRISMA guidelines (33) is shown in Figure 1.

Number of publications over time

A total of 27 publications examined caregiver burden or unmet needs (Figure 2). There was a significant increase in the total number of publications over time (IRR = 1.105, 95% CI = 1.002 - 1.219; p=0.0459).

Number of measurement, descriptive and intervention studies

Almost all of the included studies used descriptive designs (n=25, 93%, (34-58)), while there was only one measurement (59) and one intervention (60) study. The single measurement study described the predictive validity of the Zarit Burden Interview for family caregivers of individuals with COPD. The intervention study reported on the feasibility and preliminary effectiveness of a customized palliative care service designed to alleviate burden in individuals with advanced COPD and their caregivers.

Characteristics of included descriptive studies

Supplementary Table 1 shows the characteristics of the 25 included descriptive studies. Thirteen of these studies were conducted in Europe (37, 40-44, 47-51, 54, 58), five were conducted in the US (34, 35, 38, 39, 45), four were conducted in Asia (46, 53, 55, 56), two were conducted in South America (36, 52), and one was conducted in Australia (57). There were a wide range of outcomes assessed. The most commonly reported outcomes included multi-domain constructs of caregiver burden measured using scales such as the Zarit Burden Interview and Caregiver Burden Inventory (11 studies, (34-36, 38, 39, 46, 51-53, 55, 56)), psychological outcomes such as depression, anxiety and stress (eight studies, (34, 37, 43, 44, 46, 50, 51, 56)), social support (five studies, (34, 43, 46, 50, 52)), quality of life (five studies, (36, 44, 46, 49, 52)), and financial or employment burdens (five studies, (35, 45, 54, 56, 58)). Only two studies explored unmet needs (53, 57).

Study designs Almost all of the descriptive studies (92%; n=23) used a cross-sectional design. Of the two longitudinal studies identified, one included only a single follow up assessment of patient and caregiver anxiety and depression at 90 days following discharge from intensive care for COPD exacerbation (37). The other longitudinal study assessed symptoms,

functioning and depression in individuals with advanced COPD and burden on their caregivers every 4 months over a 12 month period (39).

Correlates of caregiver burden. Just over half of the descriptive studies (56%; n=14) examined the predictors of caregiver burden. Five studies (34-37, 43) examined caregiver demographic or psychosocial factors which were associated with the degree of caregiver burden. Four studies (40, 44, 51, 55) measured the patient demographic, disease, or psychosocial characteristics which were associated with caregiver burden. Five studies (39, 46, 49, 50, 52) included assessment of both patient and caregiver characteristics which were associated with caregiver burden.

DISCUSSION

COPD imposes significant physical and psychosocial burdens on both the individual diagnosed and their family. Providing informal care to an individual with COPD involves a range of tasks which can take a considerable toll on the caregiver's well-being (11-13). This review aimed to examine the research effort which has been directed towards understanding and addressing the burden and unmet needs associated with caring for a patient with COPD. We compared the extent of research effort directed towards the measurement of caregiver burden, identifying the prevalence or predictors of caregiver burden, or testing interventions to support caregivers of COPD patients. We also examined whether the type of descriptive studies conducted provided the information necessary to develop interventions with a high likelihood of alleviating caregiver burden.

Relative volume of each type of research

The findings of this review indicate a paucity of research examining issues related to the wellbeing of caregivers of COPD patients, despite the substantial burden borne by them. While it is encouraging that the volume of research output has increased over time, only 27 studies have been published in the last decade. This reflects the relatively recent recognition of the contribution of caregivers to meeting patients' complex care needs and achieving patient outcomes (30).

The vast majority of studies were descriptive (n=25), with only one measurement and one intervention study identified. Without measures that have been rigorously developed and tested for this population, the evaluation and comparability of outcomes from descriptive studies is compromised. The paucity of measurement studies may reflect difficulties in carrying out this type of research. Measurement research requires extensive skill in psychometric evaluation as well as considerable financial resources (61). Nevertheless, new tools must be developed or psychometric quality of existing tools confirmed so that burden and unmet needs of caregivers of individuals with COPD can be reliably and accurately assessed.

Similarly, only one study reported the results of an intervention that aimed to improve caregiver outcomes (60). This was a feasibility study that did not include a control group, limiting interpretation of outcomes. A number of factors may have contributed to this paucity of intervention research. Firstly, it may reflect the limited availability of validated tools for assessing burden in this caregiving group. To adequately assess whether the intervention has been effective in improving outcomes, reliable and accurate measures are needed. There may be a reluctance to conduct intervention research until rigorous measures of caregiver burden have been tested. Secondly, carrying out high quality intervention research necessitates

careful and rigorous methodological design, which requires significant expertise and collaborative input, which may not be widely available across research groups. Thirdly, research outputs, such as peer-reviewed publications, may not be as readily obtained for intervention studies as descriptive studies due to the time required to develop and implement interventions, and the reluctance to publish null findings. Finally, intervention research is usually more costly than descriptive research.

Can the types of descriptive research performed inform intervention development? Perhaps a more likely reason for the lack of intervention research is the limited scope of the research directed towards understanding the characteristics of COPD caregiver burden and needs. The vast majority of descriptive research was cross-sectional, with only two longitudinal studies identified. One study included only a single follow up of patient and caregiver burden 90 days following discharge from hospital, while the second study included multiple follow-ups of patient and caregiver burden across a 12 month period. Given patients with COPD live with the condition for many years, these time periods are insufficient to detect changes over time in caregiver burden. Therefore there is very limited data upon which to base judgements about the critical time points at which to intervene. The scarcity of longitudinal research may be due to the time-consuming nature of these studies relative to cross-sectional studies. The slow progression of COPD also contributes to difficulties in capturing changes in caregiver burden over time, as this may occur very gradually over a number of years.

Further, only fourteen studies examined the caregiver or patient factors associated with the degree of caregiver burden. To identify the groups of caregivers which are most in need of support, it is first necessary to explore the caregiver demographic and psychosocial characteristics and patient disease characteristics which are associated with increased levels

of caregiver burden. However, only five of studies examined both caregiver and patient factors that may contribute to caregiver burden. This severely limits the evidence that can be used to design interventions for the groups of caregivers who are most in need of assistance.

Future directions

The increasing prevalence of COPD, coupled with the growing body of literature demonstrating the debilitating effect of caring for a patient with COPD, suggests there is an urgent need to develop and rigorously assess strategies designed to reduce caregiver burden and unmet needs. There has been growth in literature examining interventions for caregivers of individuals with other chronic illnesses, with one systematic review finding a significant increase in the volume and methodological quality of interventions to support informal caregivers of cancer patients and patients in palliative care (62). There may be scope to adapt and rigorously evaluate evidence-based strategies from other chronic conditions to caregivers of individuals with COPD.

Limitations

Only studies published in peer-reviewed journals in English from 2000 onwards were included in the review. As a result, the total number of studies included in the review may underestimate the total body of literature. In particular, the paucity of measurement and intervention research found may be at partially attributed to the date restriction used. For instance, measurement tools may have been developed and tested for this population prior to 2000. It is also possible that publication bias away from negative trials (63) may have explained the lack of intervention research identified. Such interventions may exist in non-peer reviewed sources, which were outside the scope of our literature search.

CONCLUSIONS

Caregivers of individuals with COPD experience debilitating burdens across multiple facets of their lives. However, the current evidence for assessing the nature and extent of this burden is limited due to a lack of research into the measurement tools that can reliably and accurately assess these outcomes in this population. There is also a concerning paucity of research into strategies which may be effective in ameliorating this burden. This lack of intervention research may be due to limitations in the type of research undertaken to investigate the characteristics of caregiver burden, which provides limited evidence upon which to design effective interventions. These findings underscore an urgent need to firstly evaluate the burdens faced by caregivers of individuals with COPD with greater accuracy, and to identify strategies to effectively support this neglected group.

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Figure captions:

Figure 1. Flow chart of review steps and reasons for exclusion.

Figure 2. Number of publications over time examining caregiver burden or unmet needs

(n=27).