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## **An Integrative Review of the Impact of COPD on Families**

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### **ABSTRACT**

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in the United States. It has an insidious onset, typically occurring after years of cigarette smoking. Many of those affected are elderly with other chronic, and often disabling, conditions. Those caring for them are often elderly family members. The objective of this article is to review what is currently known regarding the effects of COPD on family members or significant others and integrate those findings into a coherent review. Nineteen articles were included in the final review, which categorized data into biographical impact, illness-related problems, the everyday burden, and consequences for the patient-partner (family member) relationship. Nurses will be increasingly called upon to provide care to this chronically ill, aging segment of the population. There is a dearth of research in this area as no longitudinal or intervention studies were found.

**Keywords:** lung diseases, obstructive; spouses; family; caregivers

### **An Integrative Review of the Impact of COPD on Families**

Research on the impact of chronic obstructive pulmonary disease (COPD) on patients' families is limited compared to research on the impact of other chronic illnesses such as cancer, heart disease, or dementia. The dearth of literature in this area is particularly noteworthy since researchers have found that COPD patients were significantly less satisfied with life, less socially active, and more disabled than persons with coronary artery disease, and have a lower mental health status than persons with peripheral vascular disease.<sup>1</sup> There is also evidence to indicate that adjustment and morale of wives with disabled or

chronically ill husbands is similar to their spouses<sup>2,3</sup> with poor health linked to having an ill spouse.<sup>4</sup>

Characterized by irreversible airway obstruction and typically occurring after years of cigarette smoking, COPD produces symptoms later in life. In 2005, 65% of patients discharged with a diagnosis of COPD were over 65.<sup>5</sup> Many of the elderly who are affected have other chronic and often disabling conditions, and the number of elderly affected is expected to rise. COPD is currently the fourth leading cause of death in the United States<sup>6</sup> and is forecasted to rank fifth worldwide in disease burden by the year 2020.<sup>7</sup> The primary reasons for the global increase in COPD include aging of the population as well as continuing smoking among men and increasing rates of smoking among women. Persons living with COPD face many challenges in their everyday lives such as dyspnea, fatigue, cough and mucus production, disturbed sleep, and altered appetite, all of which can negatively impact life quality.<sup>8-12</sup> Mobility is greatly restricted by shortness of breath, severely curtailing the patient's ability to perform usual activities. Patients with COPD experience psychological distress, have high rates of anxiety and depression, and impaired cognitive functioning.<sup>13,14</sup>

Families who live with and care for COPD patients must also deal with these challenges as, increasingly, society expects care and support of chronically ill elders to be provided by the family.<sup>15</sup> Because many COPD patients are elderly, it is generally older family members who provide this care and support. The extent to which family members are willing and able to assist with daily activities and provide emotional support can greatly affect the quality of life for persons with chronic illness.<sup>16</sup> Presence of a significant other in the home is important to the COPD patient's adjustment and ability to cope.<sup>17,18</sup> Family members are generally available in a hierarchical order, with the spouse being the most likely person to provide care.<sup>19</sup> In a nationally representative survey completed in the United States, Langa et al.<sup>20</sup> estimated that carers of those with chronic lung disease contributed 5.1 hours per week of "informal care" when compared to those without lung disease. This represented an annual cost of over \$2 billion dollars. While these numbers indicate that families provide a great deal of care for their family members with COPD, current knowledge of the impact on families of living with a COPD patient has not been integrated into a coherent whole. Such an integration may help to identify particular areas needing further elucidation. The purpose of this article is to review current knowledge regarding the impact of COPD on families and to identify the gaps in that knowledge.

## **Method**

An integrated literature review is used to bring together research findings in a coherent fashion in order to enhance their applicability and use in evidenced-based practice. In diseases like COPD where research on family members is limited, this technique is especially important. The research and theoretical literature that does exist is difficult to synthesize because of differing

methodologies, small sample sizes in many studies, varying groups of family members or significant others included in the research, lack of descriptive characteristics for some samples, and the varying or unidentified stages of patients' illness severity.

The databases PubMed, CINAHL, and PsycInfo were searched. MeSH terms *pulmonary disease, chronic obstructive AND spouse\* OR family OR caregiver\**, were used to search PubMed. CINAHL headings *lung diseases, obstructive, AND family, OR spouses, OR caregivers* were used for searching. Keywords were not used in PubMed or CINAHL because their use is less inefficient and may not produce useful results, especially in the CINAHL database. Key word searching using combinations of *COPD, spouse, family, and caregiver* was used in PsycInfo. The limit of English language was set for each search. Each of the searches was run separately using COPD and one of the terms family, caregiver or spouse. The searches were then combined using the search history in order to eliminate duplicates in the individual database searches. The reference lists of each article included in the final review were also examined in order to locate any articles that might not have been identified electronically. Criteria for inclusion of articles were that they (1) focused on the family's experience of living with a COPD patient ; (2) did not include asthma in the definition of COPD; (3) had either a qualitative or quantitative research design or were theoretical or review articles judged to be appropriately derived from previous knowledge; and (4) were peer-reviewed. For the purposes of this review, family was defined as relatives or significant others who live with the patient and may or may not provide care. Articles were limited to English language. No limits were placed on years searched because medical management of COPD has not changed significantly over the years. Unlike cancer and heart disease in which new surgical techniques and other therapies have altered their trajectories, medical therapy for COPD continues to focus on symptom management and maintenance of functional status.<sup>21</sup> Databases were searched from their electronic inception. PubMed dates searched included 1957 to February, 2009. CINAHL dates searched included 1970 to February, 2009. PsycInfo was searched from 1971 to February, 2009. Articles were included if they focused on patients, as well as family members of COPD patients, as long as they provided significant information related to family members.

The initial search yielded 170 potentially relevant abstracts in the three databases, many of which were repetitive. Abstracts were then further reviewed based on the inclusion criteria. If deemed relevant, the entire article was obtained and reviewed. Forty-five articles were examined. A total of 19 were included in the final sample 24 – 40, 42 – 44 . The method of Whittemore and Knafel<sup>22</sup> was used to perform the data analysis. In this method, the author attempts to integrate the findings from all the studies into a meaningful whole and not just list the results of each study article by article.

## Results

Three factors that may affect the applicability of findings for evidence-based practice are (1) time; (2) culture; and (3) similarity of patients or families in terms of attributes such as age, gender, or severity of illness. Of the 19 articles included in the final sample, one was published in the 1980's; five in the 1990's; and 13 in the current decade. Six of the articles were based on samples of patients and families living in the United States; the remaining 13 were from other countries. Of the 13 articles published in the current decade, only two were based on patients and families from the United States. The majority of family members studied were women and spouses. The mean age of family members was over 65 in nine of the studies. In four of the studies, the mean age was over 55. In the six in which caregiver age is unknown, one was with patients whose mean age was 77.4 and two gave age ranges from 47 – 69 and 45 – 60. None of the articles were excluded because of age of persons in the sample, rather any identified differences based on age will be reported.

Twelve of the articles were descriptive, correlational, quantitative studies; six used qualitative methods; and one used a pre-test/post-test design. The latter study sampled families only once on two variables in the pre-test phase of data collection. No longitudinal or intervention studies focusing on families or caregivers of COPD patients were found. Of the 19 articles included in the analysis, only eight focused exclusively on the family member. The remainder focused on the couple, the family, or the patient. Articles that focused on the patient were reviewed if they included relevant information regarding the impact of COPD on family members. Some of the articles using quantitative methods also reported relevant qualitative information. In at least two instances, authors examined the same data set twice in different articles, each with a slightly different focus.

Relevant data were extracted from all the included articles and data matrices were constructed. Repeated examination of the data revealed an evolution in the focus of the research over time. In the 1980's, the lone article used a stress and adaptation framework to compare stress levels between wives of COPD patients and wives of those who did not have a chronic illness. In the 1990's, all of the studies used a correlational, cross-sectional approach to describe or predict outcomes in family caregivers. In 2002, the first qualitative study was published, aiming to give a holistic description from a spouse's perspective.

Most of the articles included in the final integrative review focused on problems of families of COPD patients. Kuyper and Wester<sup>23</sup> developed a classification system for problems of families of those with chronic illness, which was a conceptual fit with the articles included in this integrative review. Their system classifies the impact of chronic illness into four categories, including biographical impact, illness-related problems, everyday burden, and consequences for the patient-partner (family member) relationship. These categories were used to integrate the findings, but the discussion was expanded to include the paradoxical effects that occur in some families as a result of these problems.

### *Biographical Impact*

Biographical impact describes the effect that the illness has on the family member's life course and identity. The biography of one's life is interrupted, which Kuyper and Wester describe as causing frustration in many people.<sup>23</sup> This is illustrated in the article by Sexton and Munro,<sup>24</sup> who surveyed 76 women, 46 whose husbands had COPD and 30 whose husbands did not have a chronic illness. Wives of COPD patients reported significantly higher stress and lower life satisfaction than the control group. The control group wives were recruited from socially active women, which possibly biased the findings in favor of greater differences between the two groups. Social and recreational activities are affected to some degree in all families. Those families able to continue activities do so within a diminishing sphere as the patient's illness progresses. This is reflected by the almost one-third of the COPD wives in the Sexton and Munro study, who stated they had given up social activities.

According to COPD wives living in what were termed dysfunctional families in one study, the biggest problems they experienced as a result of their husbands' illness were life-style change and worry about leaving their husbands alone.<sup>25</sup> Wives in all situations, whether dysfunctional or not, experienced feelings of anxiety ranging from constant fear of ever leaving the husband to limiting travel because of the husband's illness.<sup>15</sup> Even though all the wives experienced these feelings, some families were able to function better and manage the effects of illness on their biographies better than others. Poorly functioning families were described as possessing poor self-identity, enmeshment, isolation from others and lack of flexibility to varying conditions.<sup>25</sup>

Family members experienced loss similar to some of the patient's losses, including loss of meaningful employment, loss of expectations of the future, loss of retirement plans, and loss of personal freedom.<sup>26</sup> The most painful loss for wives in the studies was the anticipated future loss of a spouse.<sup>27,28</sup>

### *Illness-Related Problems*

Illness-related problems have an impact on the everyday life of family members and result from the direct effects of the illness on the patient. Specific consequences of COPD, such as cough and mucus production, disturbed sleep, altered appetite/weight loss, and, in particular, shortness of breath necessitate changes in the patient's usual activities. These effects often lead to reciprocal changes for partners when they take over activities previously performed by the patient. These activities include mowing the grass, managing finances, cooking, cleaning, or gardening. A significant portion of the wives of COPD patients related that their husbands were dependent on them for activities of daily living. Additionally, they also indicated that they had taken on more new roles and responsibilities. Other family members described themselves as taking on the roles of doctor, nurse, psychologist and carer in the last year of a patient's life.<sup>15</sup>

In terms of coping with illness-related problems, only 37% of the wives with ill spouses relied on friends for help with problems, whereas 73.3% of the control group wives in Sexton and Munro's study did.<sup>24</sup>

Illness-related problems may be caused by the technologies used to manage COPD. Although often necessary to relieve symptoms, technologies such as long-term oxygen therapy (LTOT) may increase the complexity of illness management and have intrusive side effects. In assessing family dynamics, however, Kanervisto<sup>25,29</sup> found that families with patients using LTOT were significantly better in the dimensions of individuation, mutuality, and flexibility than were those not using LTOT. This result may be somewhat surprising, but also may reflect a required adaptation to a chronic illness by a healthy family. Once COPD patients require LTOT, they are generally in the severe to very severe stages of the illness and will be more dependent on family members in all aspects of daily living. In a participatory qualitative research study, Jonsdottir has described this "healthy" functioning as finding coherence in life with symptoms and treatment.<sup>30</sup>

### *The Everyday Burden*

The uncertain nature of the illness trajectory of COPD places a particular burden on families who have to learn to monitor changes in the patient's body and to discern between kinds of attention needed to respond to symptoms.<sup>30</sup> It is very difficult for family members to know when an exacerbation is looming or when sick means sick enough to require a visit to the health care provider.

The uncertainty of living with a person with COPD puts the family member on an emotional roller coaster that adds up to an everyday burden for them. Researchers have described this everyday burden in terms of outcomes, including actual illness burden, loneliness, depression, mood, or amount of disturbance. They have further attempted to delineate factors associated with functioning in these areas,<sup>28,31-35</sup> including types of caregiving tasks performed and emotional support required by the patient.<sup>32</sup> The task of making decisions and watching to prevent activity the patient cannot perform because of breathing problems is seen as particularly onerous. This again relates to the uncertain nature of COPD and the difficulty in predicting when exacerbations will occur.

Similarly, duration of care in terms of months or years performed and hours spent caregiving were related to higher burden scores.<sup>35</sup> Younger caregivers experienced more burden than older caregivers if categorized as  $\leq 55$  years of age. White caregivers experienced higher burden scores than black caregivers while scores were similar in male vs female or spouse vs non-spouse caregivers.<sup>31</sup>

The major worry of all COPD family members was the patient's condition and whether or not the patient would recover from acute exacerbations. Uncertainty is

a result of the unpredictable nature of the illness, never knowing when an exacerbation is coming and never really knowing when a particular coughing episode might indicate a crisis is threatening. The most painful loss was the anticipated, eventual loss of the family member, described as the dreadful prospect of a single life for wife caregivers or worry about the husband's making it through the night.<sup>28,36</sup> It is impossible to predict when the final exacerbation will occur. Because of the uncertain nature of the illness trajectory, carers found it especially important to have a "back-up," someone in the health care system to contact in a crisis.<sup>37</sup> Seventy-eight percent of carers of those who didn't know if the patient would die within the year stated that they would have liked to have had that information related to prognosis.<sup>38</sup> Family members who were caregivers also reported that they were unprepared to take on a caring role and did not initially understand COPD and its implications.<sup>15</sup>

Some authors described how families coped with the everyday burden of illness. Most families described their coping strategies as taking one day at a time or as taking things as they come.<sup>39,40</sup> The illness experience had a paradoxical effect on some couples and families, who saw it as an opportunity to live life more fully or to experience a positive side to caregiving.<sup>30,36</sup>

#### *Consequences for the Patient-Partner (Family Member) Relationship*

No studies have been conducted that examine the quality of the relationship between patients and family members prior to the patient's developing COPD. Increased togetherness imposed by caring for an ill family member may be an important issue for family members of any chronically ill patient.<sup>41</sup> Many of the patients in the studies included in this review were retired, often related to illness. Retirement is an important event, which may be both central to the illness experience and an important developmental task for older families, especially couples. Retirement may not only have financial effects on a family, but may also affect every day, mundane aspects of living, disrupting the normal day's rhythm of the partners. For women, having another individual present within the home "telling them what to do," when they previously had a solitary homemaking role prior to a husband's retirement, may require an adjustment. This disruption may not be related solely to the effects of the illness but also to close proximity. It may be need for space and privacy that produces strain in addition to the demands of caregiving. Wives as caregivers identified the problem of losing their freedom while being able to get out of the house for more than eight hours a day was associated with lower burden scores.<sup>35,36</sup>

Leidy and Traver studied adjustment and social behavior of older COPD patients from the patient's and the family's perspective. In addition, they compared families' perceptions of COPD patients to perceptions of families of persons without COPD. They found no difference in perception of whether socially expected or free-time activities were impaired. However, relatives of COPD patients were significantly more dissatisfied with the family member's free-time

activities. Family members of COPD patients also reported lower levels of patient adjustment.<sup>42</sup> In the study that specifically addressed marital adjustment, partners were, on average, satisfied with their marriages. Partner marital adjustment was associated with increased patient physical functioning.<sup>43</sup>

It may be difficult to unravel whether effects on a relationship are due to imposed togetherness, caretaking activities, or impaired communication. Cognitive impairment, defined as patient-reported poor memory, was the only symptom in one study significantly influencing family health. The author surmised that, even when physical attributes such as shortness of breath are the hallmark of a disease, it may be cognitive aspects that strain family relationships.<sup>44</sup> Some spouses have also reported an effect on sexual relationships.<sup>24</sup>

### **Limitations**

The categories of this organizing framework are not completely mutually exclusive so integrating findings into one part of the classification does not mean they could not also fit under another part. Like any other work that uses qualitative methodology, subjectivity is inherently part of the process. Maintaining an audit trail is one way to address credibility and dependability in integrative reviews. The author has maintained search results, retrieved articles, and data matrices. Only one person performed the integrative review. Increasing the number of reviewers may decrease the possibility of bias; however, leaving an audit trail also allows the ability to follow decisions made. Making choices about inclusion or exclusion of articles is inherently subjective.

### **Implications for Nursing Practice and Research**

This integrative review found that the impact on families of having a member with COPD could be organized into four categories, including biographical impact, illness-related problems, everyday burden, and consequences for the relationship. The impact on biography centered around experiences of loss in several aspects of families' lives. Illness effects were seen particularly in the area of social and recreational activities while uncertainty was a burden for most families, particularly related to not knowing when an exacerbation might occur. Most families caring for members with COPD functioned well, even with little support from their social network or the health care system. Support from health care providers that is there when the family needs it seemed to be especially important in helping families deal with the consequences of living with a person with COPD. Because of uncertainty, the knowledge that someone will be there during a crisis may be one of the most important needs of family members, particularly because of the unpredictable exacerbations that occur with COPD.

No studies were found that follow families over time to learn how they function over years of coping with the patient's illness nor were any intervention studies found that aim to facilitate families' providing care to COPD patients in the home.

This dearth of research has been reported by other authors.<sup>45</sup> In examining various approaches to providing care to COPD patients such as home-based respiratory care or telephone services, family focus was not included in any of the studies.<sup>46</sup> As COPD continues to increase around the world, especially in the aging population, this lack of attention must be addressed in the nursing literature.

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