



## Active carers: living with chronic obstructive pulmonary disease

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# Active carers: living with chronic obstructive pulmonary disease

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## Abstract

It has long been recognised that the majority of care provided in chronic illness comes not from health and social care professionals, but from family and friends. One such illness is chronic obstructive pulmonary disease (COPD), a leading cause of morbidity and mortality in the developed world. To explore the specific care needs of informal caregivers of patients with advanced COPD, interviews were conducted with seven active family caregivers. Interviews were taped, transcribed and content analysed to obtain the caregivers' needs. Results confirm that family caregivers provide direct care with little support and assistance. Participants reported restricted activities of daily living and some emotional distress. There were knowledge deficiencies among caregivers relating to the COPD illness trajectory and little awareness of the potential of palliative care. Family caregivers need social and professional support while caring for a patient at home. This would help to ensure that their physical and emotional health does not suffer. There is a need to devise interventions to ensure family caregivers are supported.

psychological burden associated with this role (Department of Health, 1995; Chan and Chang, 1999; Elkington et al, 2005; Eriksson and Svedlund, 2006; Barnes et al, 2006; Seamark et al, 2007). It is of little surprise, therefore, that family caregivers are increasingly recognised as being in need of care themselves (Harding and Higginson, 2001; Morris and Thomas, 2001).

The majority of research has tended to focus on the activities caregivers undertake, describing the burden and costs experienced (Zapart et al, 2007). Less attention has been given towards exploring the views of those caring informally for people with advanced COPD in the home. For example, in their study of 26 wives of patients with COPD, Ross and Graydon (1997) reported restricted social life and the need for support. Later, Bergs (2002) explored the experience of six women caring for their husbands with COPD in Iceland, using in-depth personal interviews. They reported feelings of isolation, loss of freedom, emotional and mental stress and marital problems. Uncertainty about the trajectory of the illness, the dying process and prospective bereavement was also a source of stress for the carer. They recognised the positive sides of care giving while recommending the need for increased social support. More recently, in Finland, Kanervisto et al (2007) explored family dynamics in patients with severe COPD (35 patients and 30 family members) and found that poor self-identity and isolation were common characteristics which impacted on the ability of families to manage in everyday life.

It should be noted that the terminology used to refer to the caregiver role is ambiguous (Barnes et al, 2006). For example, Houts et al (1996) adopted the term 'family caregiver' to refer to people who are not health professionals and who are not paid for their caregiving services. More recently in the UK, the Department of Health (2006) have employed the term 'carer' to differentiate the family role from the formal care provided by health and social care professionals. In this article, the term 'family caregiver' will be used to describe the informal care provided for COPD patients.

**C**hronic obstructive pulmonary disease (COPD) is an umbrella term for chronic bronchitis, emphysema and other chronic lung conditions, and is ranked fourth as the leading cause of morbidity and mortality worldwide (Mannino, 2002). In the UK there are around 900 000 diagnosed cases of COPD (National Collaborating Centre for Chronic Conditions, 2004). Changes in the delivery of care for patients with chronic diseases, for example, the trend towards community-based care combined with advances in medical technology, have resulted in the majority of care being delivered in the home by family caregivers.

Family caregivers are recognised as an important component of palliative care (Thielemann, 2000; Proot et al, 2003). Most take on the supportive caregiving role with little or no training, yet are involved in an array of complex and challenging tasks, such as medication administration and symptom assessment, as well as assisting with activities of daily living (Aranda and Hayman-White, 2001; Thomas et al, 2002). Consequently, research has revealed a significant physical and

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Informal family caregivers of patients with advanced COPD provide an important perspective on understanding palliative care service requirements as they, too, are recipients of care. This article reports on a study of family caregivers of patients with advanced COPD at home.

### Methods

A descriptive, qualitative method design, with semi-structured interviews, was used to explore the needs and experience of family members caring for a person with advanced COPD in the home. Good practice was adopted in obtaining informed consent and respecting participants' privacy and autonomy. Ethical approval was obtained from the Office for Research Ethics Committees in Northern Ireland. Local research governance procedures involved review and approval of the full research proposal before data collection.

### Sample

Family caregivers were recruited by the respiratory nurse specialist (RNS). Purposive sampling was used in this study as the family caregiver was identified by the RNS as the primary family carer from medical records. Inclusion criteria for family caregivers required the patients to be agreeable to their prime carer's participation; the giving of informed consent; to be able to speak and read English; and to be over the age of 18 years. To ensure confidentiality, the RNS disseminated a letter of invitation, participant information pack and consent form to family caregivers which explained the research. Once the consent form was returned, interviews were arranged and undertaken at a time and place convenient to each participant. All consented to their GP being contacted if the researcher felt that a significant issue was raised during the interview. Any carer was excluded if the patients did not agree to their participation, if they were unable to give informed consent, or had communication difficulties. In total, 11 carers were invited to participate in the study, of these seven agreed to take part.

Participants completed a demographic questionnaire giving their age, gender and experience as carers. An interview guide, based on relevant literature, was used to explore each patient's illness and symptom history, and each caregiver's experience of caregiving, informational, educational, psychosocial and spiritual support needs. The demographic questionnaire was subject to inter-rater reliability with two researchers employed to verify the findings. A semi-structured interview schedule was reviewed by experts within the field of COPD and palliative care and by carers and patient representatives to establish clarity of

language, acceptability and relevance of the questions. Interviews were conducted by a hospice nurse and generally lasted no more than one hour. With permission, individual interviews were audio taped and supplemented by field notes. All interviews were undertaken within the carer's own home. Participants were assured that they could stop the interview at any time and were given written details of available support services. Several participants did become upset during the interview, but asked to carry on, stating that it was helpful to speak about their experiences.

The transcribed data were content analysed using the framework by Miles and Huberman (1994), which involved data reduction, data display and conclusion drawing and verification. All transcripts were read, notes made, themes and categories generated, codes assigned and meanings grouped together. This approach is similar to the method of constant comparison devised by Glaser and Strauss (1967), which involves the process of comparing and contrasting data to establish patterns, then questioning these patterns as part of an ongoing analytic process. Two researchers independently generated categories and themes from the data. Responses to the demographic questions were summarised using descriptive statistics.

### Results

The majority of family caregiver subjects were female ( $n=6$  of 7), married and aged between 55–65 years of age; only one was aged 30 with young dependents. Four were caring for their spouse/partner, two for a parent and one for a sibling. Two participants had been caring for one to two years; three for two to four years; and two for more than four years. The themes merging from the interviews included the following:

- Impact of family caregiving
- Unmet support needs
- Carers' perceptions of patients.

#### *Impact of family caregiving*

Caring for a patient with COPD had affected all participants physically and psychologically. They suffered fatigue, loss of concentration and lack of sleep due to the patient's need for constant care. Managing daily life was problematic. The unpredictability of the future was a major cause for concern, as not knowing what to expect meant that, in many instances, carers felt anxious, living in constant fear of leaving the patient in case they suffered an acute exacerbation in their absence. There were several instances when carers described feelings of helplessness, guilt and frustration about their isolation, their lack of time for themselves and their perceived lack of control over their lives.

*‘Carers described feelings of helplessness, guilt and frustration about their isolation, their lack of time for themselves and their perceived lack of control over their lives’*

*‘In this study, many family caregivers assumed the caregiving role without adequate information on the patient’s condition or prognosis’*

‘Our life has come down. The two of us used to go out dancing. We loved dancing and then it all stopped.’ (AC2)

‘You’re never in charge of your life again, because you are constantly worried about that person. You are mentally worried all the time about are they still breathing? Is everything OK? Now you mentally can’t rest and relax because you think, is this their last breath?’ (AC11)

Carers disclosed how much their lives and social identity had changed. They reflected upon the multiple roles they adopted when caring for their relatives. In addition to that of spouse, offspring or sibling, they also took on the role of the nurse, doctor, and psychologist and carer. They outlined a wide range of caring activities they provided, such as cooking, feeding, dressing, medication, symptom assessment, liaison with health professionals and financial management. Carrying out these roles often led carers to feel that their own identity was lost and, in some cases, resentment at having to take on another caring role after having previously cared for another relative.

‘It’s like having another child sometimes because you are sort of responsible and I feel he is my responsibility. I feel that he is not anybody else’s responsibility and you are having to plan ahead ... all the time.’ (AC6)

‘I feel I have a number of roles I have to maintain and then I have them ... to separate from my children and partner, it’s extremely difficult, it’s been the most demanding thing I’ve ever had to experience. And I don’t know how long I can go on. I am trying to survive with what I have, what services I can have to help me, anything but put her in a nursing home.’ (AC11)

‘One of the social workers said to me, “What do you do if you are sick?” Says I, “You just carry on – what else do you do?” [He] can’t do it and you have to do it ... sometimes I’m frustrated ... God forgive me for saying it, [he] can’t help what’s wrong with him, but sometimes I am angry ... you know, I’ll say: “Why? – why is [he] like this?” Because we had a reasonable life before this, you know.’ (AC4)

Despite the burden, carers also expressed a strong sense of duty to care, and commented on the satisfaction they felt in being able to do something useful.

‘There’s no good taking off [going away] and saying aw I can’t be bothered with this, I’m away ... There’s some women can’t be bothered with it. That [going away] would never have entered my head.’ (AC2)

‘I just love him and I find that every day when I see him, what else could I do to try and make him a wee bit ... better? It’s very satisfying to know that he appreciates what I do and it’s nice to know that you are helping someone.’ (AC6)

Although the caregiving role had a serious impact on lifestyle, causing significant changes, family caregiving was found to be rewarding, with caregivers demonstrating a certain resilience.

### *Unmet support needs*

Carers revealed that they were unprepared to take on a caring role and that they did not initially understand the nature of COPD and its long-term implications.

‘I’ve never been sat down and told. I think about the admissions and that there, no-one had warned me about this, nobody had said, the admissions will come more rapidly. It’s just one of these things. When I go to the hospital and speak to the consultants I can’t get to see them, you know. They are trying new medications and nothing was explained to me. Nobody had time. I just find that very frustrating.’ (AC11)

This was despite the fact that they frequently had to make judgements regarding the patient’s condition and about whether or not professional intervention was required.

All commented on the sporadic information obtained from health and social services on the condition, its consequences and the care patients required. Carers also expressed a lack of knowledge about what services were available for the patient and also for themselves. While support and access from health professionals, especially the primary health care team, was identified as important, carers revealed that they were reluctant to ‘bother doctors’ unless it was absolutely necessary.

‘They are very good and I know I can ring them up. The doctors are great, they are marvellous; you can ring or he’ll even ring to see if you are alright. That means an awful lot. When he is doing well I don’t like to bother them. When you need a person, that’s the time that you ring, when he is not great.’ (AC9)

Participants recalled home visits by community

respiratory nurse specialists, dietitians, physiotherapists and occupational therapists, but some did not have a social worker. Most carers did not have any practical support and relied instead upon extended family support. Only two carers obtained a home help; however, this was only for 20 minutes during the day and they found this difficult to organise around their relatives' frequent admissions to hospital.

Long waiting lists resulted in carers having to purchase equipment themselves, such as wheelchairs. Lack of knowledge about how to access financial support resulted in numerous problems for the family. One participant commented on the unpredictability of COPD and its impact on benefit entitlements.

*'I think the main thing I need as a carer is somebody to tell me what I am entitled to or what he is entitled to that I could use to his benefit. If I was getting an allowance I could use it to the benefit of him in that when I go away he wouldn't be worrying that he is putting it on to anybody.'* (AC6)

*'If my mum is in hospital for more than five weeks you are not supposed to claim any benefits ... having COPD means that her admissions are unstable and can vary and they can't give you a discharge date because things can dramatically change. It actually costs me more money when my mum is in hospital because of the petrol going up and down every day and making sure she has all she needs ... But, unfortunately, COPD is not classed as a terminal illness.'* (AC 11)

### *Carers' perceptions of patients*

Most participants were concerned that their relatives struggled emotionally and physically with the effects of COPD. Over the years, they had witnessed their relatives' gradual deterioration in health and their increasing symptoms of breathlessness, frequent chest infections, coughing, loss of weight, energy and appetite, tiredness and gradual loss of mobility and ability to do day-to-day tasks.

*'[He's] completely and utterly spent, you know ... He couldn't even talk to me because he was just completely breathless, lethargic and you know just no spark of life in him ... He was down because when you are not well we feel sorry for ourselves but on top of feeling sorry for himself he hadn't the energy.'* (AC6)

*'He's very bad at the minute now. As soon as he moves he's completely breathless.'* (AC10).

*'What we have up against us now is the amount of chest infections, they are coming more rapidly, frequently, and the weather. The weather's a big big issue, it's either too humid for her in the summer, and in the winter it's either too frosty in the air, too damp in the air and that all triggers a chest infection. That's a big factor.'* (AC11)

They related how their relatives had become highly dependent on oxygen, nebuliser use and constant antibiotic medication and, over time, had become increasingly housebound and frequently admitted to hospital. Participants highlighted their relatives' anxiety when breathless, particularly at night, their low or depressed feelings and their sense of hopelessness and frustration at their quality of life.

*'She would get anxious when she is breathless. It would be good if she could get a wee anxiety pill or something to take at night ... she's lost confidence you know, I think she has. Although I know it's very hard when you can't get a breath ...'* (AC7)

However, the carers also felt that their relatives had tried to 'get on with it [life with COPD]' as they felt that 'nothing more could be done' for their condition. Uncertainty about the trajectory of the illness was a source of stress to the patient and also for the carer.

*'There were days I thought to myself, where are we going from here? But we mastered it together and tried to do things at his pace.'* (AC9)

Participants were unfamiliar with the dying process and most participants were not aware of palliative care services, but thought that it would be relevant for patients with COPD.

*'I've heard of it [palliative care] but to be honest I never understood what the word meant.'* (AC6)

### **Discussion**

Caregivers provided a range of care contributing significantly to the patient's quality of life. They highlighted the range of physical symptoms experienced, especially breathlessness, fatigue and panic attacks; in response, they adopted multiple roles to provide physical and emotional support. The roles family caregivers adopt when caring for a chronically ill person have been reported elsewhere (Eriksson and Svedlund, 2006; Barnes et al, 2006). In this study, many family caregivers assumed the caregiving role without adequate information on the patient's condition or prognosis. As has been

*'Although the caregiving role had a serious impact on lifestyle with significant changes, family caregiving was found to be rewarding ...'*

previously reported (Aranda and Hayman-White, 2001; Thomas et al, 2002), family caregivers are involved in complex care tasks and make clinical judgements on the patient's condition. Few realised the full extent, or consequences, of the illness.


The findings elicited from family caregivers living with COPD reflected explorations of caregivers of other chronically ill individuals. For example, caring for patients with advanced chronic illness results in mental and physical burdens on the caregiver (Bergs, 2002; Seamark et al, 2007), with their daily life being restricted (Ross and Graydon, 1997) and carers experiencing difficulty in finding time for themselves (Chan and Chang, 1999; Proot et al, 2003; Zapart et al, 2007). Many family caregivers have highlighted feelings of suffering and helplessness. Insecurity about the future was also a prominent feature, with carers living in constant fear of leaving their loved one. Yet, despite such fears, they wanted to continue providing care at home, recognising this was their chance to do something for the patient.

Lack of support was strongly voiced, with carers expressing a lack of knowledge about the availability and sources of services. Carers were reluctant to bother health care professionals, instead only seeking contact when acute episodes occurred, a finding also reported by Morris and Thomas (2001). Moreover, while COPD is a progressive, incurable illness, carers lacked information on palliative care, which suggests the need for future efforts to improve palliative care for patients and carers.

### Limitations

It cannot be assumed that family informants reflect patients' views and it is acknowledged that they may suffer more than, and in different ways to, patients (Higginson et al, 1994). Families are uniquely qualified to define priorities to improve palliative care, yet have been rarely asked to do so (Hanson et al, 1997).

### Conclusion

Informal carers of patients with advanced COPD received inadequate support and have a range of unmet needs that are rarely acknowledged. Adopting the family caregiving role has implications for family members' own health and wellbeing. The findings of this study provide an initial understanding of the experiences and needs of caregivers and family members of patients with advanced COPD. There is a need to educate and support family caregivers to ensure that they can provide care in the home that enhances the patients' and their own quality of life. 

### Key words

- Caregivers
- Home care
- COPD
- Palliative care

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