Living with failing lungs: the doctor–patient relationship

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Objective. The aim of the present study was to explore the perceptions and needs of chronic obstructive pulmonary disease (COPD) patients by a qualitative study using semi-structured interviews.

Methods. Sixteen patients with a diagnosis of COPD (age range 59–75 years) were recruited from two sample frames. One group were under the care of GPs and the second had received in-patient care previously at a district general hospital. Participants had either moderate or severe impairment of respiratory function identified by spirometric testing [forced expiratory volume in 1 second (FEV1) <50% of predicted value].

Results. Primary and secondary care samples were chosen in the hope of identifying various aspects of care. However, the patients in this study primarily chose to discuss their relationship with their GP when considering aspects of their lives as a COPD patient. The most significant findings related to the respondents’ chronic patient status, their ability to control symptoms and expectations of health care support. All these factors were connected to their perceived relationship with their GP.

Conclusions. Doctors, as gatekeepers of health care resources, were seen to have immense power over the patients’ lives. The need to be perceived in a good light by their doctor was intensified by their low self-esteem, poor control of symptoms and their chronic disease status. The majority of patients expressed a need to take a more active part in the decision-making processes involved in the management of their disease. A more balanced doctor–patient relationship could develop if frank and open discussions are based upon a shared decision-making approach.

Keywords. COPD, coping, patient’s perspective, relationships.

Introduction

Chronic obstructive pulmonary disease (COPD) is a slowly progressive disorder characterized by obstruction of the airways which does not change markedly over several months.1 COPD is a disabling disease with poor prognosis and no cure. Despite the palliative nature of the disease, little in the way of terminal care or support is available for this group of patients. Current medical treatment relies on managing exacerbations and symptom control.2 The degree of respiratory impairment correlates poorly with the patient’s ability to cope.3 Research, and anecdotal evidence in daily practice, has supported the health care professional’s view that social factors and the patient’s individual personality significantly affect how the long-term consequences of this disabling disease are managed by the patient.4,5 These views enable all health care professionals to justify some patients’ failure to cope. It is possible that poor self-esteem, loss of hope and the fear experienced by these patients reduce their ability to be assertive and seek the support that they need. Equally, individuals seen as ‘sick’ or with a ‘chronic disease status’ have been identified as having a poorer value in society.5,7 These factors, compounded with the self-inflicted nature of COPD, result in social, psychological and medical crises in their illness progression.8

Current research has identified the need to empower the patient and suggests that this can result in not only informed and effective decision making but also a significant improvement in patient satisfaction and treatment compliance.9,10 A good doctor–patient relationship is seen as an important component in the patient’s ability to cope, yet there remains a disparity between the two groups’ perceptions and expectations during consultations.11,12

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Doctors have been shown to be poor predictors of patient need. Some patients value explanation and continuity of care over technical interventions and competence. This has added importance for the COPD patient, as opportunities for successful interventions are limited. The primary care team play a very large part in the patients’ ability to cope with COPD, not only from the daily medical management, but also as gatekeepers to other health care resources. Despite these findings, current trends towards informing and empowering the patient are slow to present themselves in daily practice.

However, it is simplistic to conclude that a better outcome can be achieved purely as a result of an improved doctor–patient relationship. Psychological and social research have identified a range of behavioural factors that individuals deploy when receiving health care interventions.

There is now a growing consensus that chronic disease patients have multiple needs that do not fit easily with the routine consultation visit. Recent research has focused on the limitations of the consultation and highlighted the doctors’ responsibility in ensuring that a successful outcome is achieved by including the patients’ agenda. Health policies over the last few years have emphasized and encouraged raising awareness of the patient’s agenda in the provision of health care. An important component in the patient’s ability to cope is that of their relationship with their family doctor and the level of support they perceive as available to them.

Doctors and nurses need to be aware of the complex perceptions that this vulnerable group of individuals hold, in order to develop a mutually trusting relationship with their patients. Patients have invested a significant amount of their illness experience with their family doctor and wish to build a trusting and mutual relationship with them. Respondents in this study perceived each exacerbation as a possible ‘life threat’ and as such hoped that their family doctor would recognize and value their individual needs. At a time when health care professionals are expected to increase their pace, it is important component in the patient’s ability to cope with COPD, not only from the daily medical management, but also as gatekeepers to other health care resources. Despite these findings, current trends towards informing and empowering the patient are slow to present themselves in daily practice.

For COPD patients, this risk is high.

Methods

Patients were recruited up to the age of 75 years with a diagnosis of COPD, and who had no other serious underlying chronic disease, serious psychiatric problems or deafness. The participants were identified from two sources. One sample was selected from a large general practice based in a town (population 12 776). Further selections of patients from this practice were then excluded from the second sample group. The second sample was identified from patients who had attended the local district general hospital (420 beds). However, the patients from the second sample were also under the care of their own GP. The two groups were selected by computer-generated random sampling methods. The sampling frames were then used to select 25 patients from each frame using sequential blocks of five potential recruits until no new recruits were needed. They were invited to participate by letter (response rate: 70%). Respondents were included into the study if their forced expiratory volume in 1 second (FEV₁) was <50% of the predicted value (moderate to severe respiratory impairment).

A focus group of six COPD patients met and the discussion was tape recorded to aid the researcher in identifying relevant topics for a semi-structured interview schedule. Focus group participants were excluded from the sampling for the main study. Both the semi-structured interview schedule and the researcher’s expertise in interviewing were refined prior to the main data collection by carrying out pilot interviews. Data collected from the focus group and pilot interviews were not used in the main study.

A patient coding system ensured confidentiality throughout the study. The researcher introduced herself as a research nurse and was not known to the participants prior to the study. The interview process was undertaken in the patients’ own homes and audiotaped. Additional notes were made immediately following the interviews. Interviews lasted between 45 and 85 minutes (average 60 minutes). The interviews explored the participants’ view of their illness. Open-ended non-directive questioning was used. The first question addressed the respondents’ perception of their quality of life and the last question asked for any other issues that might not have been covered during the interview (Table 1).

Analysis of interviews

All tapes were transcribed verbatim by the researcher. Transcripts were analysed to identify themes and subthemes, and a simple thematic analysis based upon preserving the uniqueness of each individual’s experiences (a phenomenological approach) was used. The data were analysed to identify common descriptive themes, which were grouped into clusters. Once data were complete and fully analysed, interpretative themes and subthemes were then identified (Table 2).

A cyclical process of interviews, simple analysis and further patient recruitment continued until no new themes appeared (Fig. 1). This occurred after 11 patients had been interviewed, but a further five patients were recruited in order to gain a greater depth and range of views within the themes and subthemes identified. The researcher re-examined field notes, interview transcripts and audiotapes, to ensure the data were ‘true’ to the stated perceptions of those interviewed. An essential validation process in qualitative research is that of ensuring that the analysis made is free from researcher bias.
bias and true to the data24 (Table 3). An additional tool was used to analyse the level of control the interviewer used during interviews. A detailed analysis of this identifies the percentage of words spoken by the interviewer and a level of directiveness score (Table 4). The Interview Control Tool is the subject of a further paper being prepared for publication by the author.

Two colleagues, one skilled in qualitative research and the other a respiratory specialist nurse, were asked to undertake validation checks during this study (agreement 89%). The process also included agreement on emerging themes identified in the transcripts.

When the analysis was completed, validation was sought from each patient. Each was presented with the analysis based upon their individual themes mentioned and their perspective as understood by the researcher. All were content with the interpretations made, although one participant’s circumstances had changed and this was noted.

Results

The average age of the participants was 68 years (range 59–75 years). The mean FEV1% predicted was 29%. This sample was broadly similar to the population group of COPD sufferers with predominately male subjects (n = 12) and no elite responder bias (Table 5). Although this study set out to identify two sample frames, it became clear that day to day care, delivered by the family doctor, was the major focus of their lives.

The issues presented in this paper are those that illuminate the relationship between the doctor and the patient with COPD and how this relationship affects the individual’s ability to cope with their disease. The results presented in this paper are part of a larger study26 and the author is unable to expand fully, within the scope of this paper, on all themes identified. In the original study, the issues relating to the doctor–patient relationship appeared in a number of different themes. For the sake of clarity, the concepts that these data illustrate have been drawn together under new section headings in this paper. A thematic framework of the full analysis is presented in Table 2.

The beginning of the doctor–patient relationship

The recurrent theme identified and discussed at length throughout this study was that of the relationship between the patient and their GP. How successful this relationship was perceived by the patient was often formed on the level of empathy and support given at the time of diagnosis. How the doctor dealt with this consultation remained in the patient’s memory, some recalling “nothing could be done” (14A), “finished” (16A) or “self-inflicted” (9A). It was clear that many experienced a strong sense of loss after the diagnosis, finding it difficult to come to terms with the hopelessness. One respondent became depressed, ignored

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³ Interpretative codes.
treatment and drank heavily before seeking further medical care.

“Suicidal for a few years. Yes, it was pretty rough, but I got over it.” (16A)

“Although, I don’t think there is any point in carrying on for the last few years, feeling like I do.” (24A)

However, for some, the relationship with their doctor appeared to strengthen over time and illnesses, particularly when a level of empathy was expressed. A sense of camaraderie with the doctor had fortified one patient.

“Pull out his cigarettes, have a fag, open the window and we would sit there. It was killing him as much as me . . . but as he said it will finish both of us before long.” (23A)

Sufferers sensitively perceived health care professionals’ expectations for improvement. On leaving hospital, one sufferer felt this was confirmed when promising to return and visit the ward.

“So he said yeah, but you could see his expression, it said . . . no chance.” (19A)

The agenda of the consultation
Each illness crisis was perceived as a potential life threat. The uncertainty in the progression of the disease and the unpredictable nature of the attacks of breathlessness left
many patients fearing that this attack could be their last.

“I am still frightened of that stuff, suffocating and not being able to breathe.” (24A)

“It don’t improve again, once you’ve got worse you stay there.” (13A)

In this study, the individuals’ attitudes about their disease were not reflected in the severity of their disease.

“I mean, that is pretty obvious, you don’t beat it. But this time I am going to make it work hard to beat me... it will have to beat me on points, it is not going to knock me out.” (19A) (FEV1 12% of predicted)

The inability to explain, or get others to appreciate, the sensations of breathlessness resulted in frustrations and anger for 15 respondents. Patients used words such as ‘exasperation,’ ‘panic’ and ‘fear’ when attempting to explain their feelings during an attack of dyspnoea. These emotions, combined with their loss of self-esteem and their sense of powerlessness, resulted in a reticence to discuss their attacks of breathlessness.

“It is like looking at the cover of a book. They say that’s a good book. Inside it’s lousy.” (16A)

The respondents in this study received very little information from their doctors. Three patients who used breathing exercises to help cope with their ‘panic attacks’ had found them of great benefit. The respondents had gained these skills without help or advice from any health care professional.

“Are there booklets that I can get, that they would sell me and draw me diagrams?” (18A)

The lack of information available was also apparent when patients were initially given inhalers or nebulizer treatments, although two respondents stated that at the

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*Developed from the level of directiveness scoring system. The analysis of interviewer’s behaviour is the subject of a further paper by the author (unpublished).

| Table 4 Interview Control Tool: level of directiveness and word count |
|------------------------|---------|-----------------|-----------------|
| Respondent code | Total words spoken | Respondent’s words (%) | Level of directiveness average score for complete transcript |
| 9A | 4365 | 84.2 | 3.3 |
| 10A | 3061 | 74.1 | 3.5 |
| 13A | 4645 | 83.7 | 3.4 |
| 14A | 5939 | 89.6 | 3.7 |
| 16A | 5857 | 83.5 | 3.6 |
| 17A | 4201 | 90.8 | 3.3 |
| 18A | 2414 | 81.3 | 3.2 |
| 19A | 4807 | 87.1 | 2.9 |
| 21A | 5104 | 89.5 | 3.0 |
| 22A | 8567 | 91.7 | 3.3 |
| 23A | 5923 | 87.0 | 3.2 |
| 24A | 5273 | 84.1 | 3.0 |
| 26A | 4248 | 79.5 | 2.8 |
| 27A | 6580 | 82.9 | 3.3 |
| 28A | 10627 | 86.8 | 3.3 |
| 29A | 4923 | 72.7 | 3.0 |

No. of questions and responses by researcher

Range 37–135
(average 80)

Level of directiveness score for interview
Range 63–416
(average 263)

Average score for interview
Range 2.8–3.7
(average 3.2)

Individual respondent’s analysis of number of questions asked, level of directiveness score given and average score for interview.

Examples of scoring system: scores 1, phrases such as ‘uh uh’ ‘Go on’ ‘In what way’; scores 2, reflecting back to interviewee their comments ‘So you asked him?’; scores 3, attention addressed to the last comment made by interviewee and continued along this line of enquiry; scores 4, probe an idea preceding the last remark; scores 5, probe by interviewer of a much earlier remark made by interviewee during interview; scores 6, introduction of a totally new topic.
time of initial diagnosis they paid little attention to the medications or instructions.

“I mean to say, they say take notice of the literature inside the box . . . because he hasn’t got one there at hand, it isn’t that he can show you how to use it.” (14A)

This reluctance to discuss their breathlessness was increased for some patients when attempting to negotiate their health care needs with their doctor. A few respondents felt confident they could implement decisions and discuss them with their doctor. However, the majority of respondents expressed the feeling of hopelessness or resignation.

“From my experience, I know they can’t help so there is no point feeling any sort of . . . animosity . . . there is no point in saying why can’t you do something for me.” (17A)

Respondents in this study perceived health centres for acute care—in their view for patients who needed immediate treatment and were very ill. Their check-ups or consultations they felt were for the doctor who had his agenda. An admission to hospital was for emergency care and, yet again, not the right place to voice their needs. Six respondents had experienced negative feelings when trying to forge a relationship with their doctor.

“I haven’t told him because he pooh poohs lots of things, you know and I think it rather puts you off a bit.” (28A)

“All he is interested in is give me a prescription, how do you feel, yep . . . you have had your 10 minutes . . . on your way.” (24A)

Respondents in this study identified a need for support and advice but were uncertain where to seek this help. All 16 patients viewed the doctor’s power over decision making for them and access to health care as paramount. Two respondents were so concerned about having discussed these issues that they telephoned the researcher following the interview to re-affirm respondent confidentiality.

“Doesn’t matter what your illness is, you have to take their word.” (13A)

“I am still uncertain . . . I wonder if I would be justified in seeing a consultant.” (9A)

Some had doubts they had not pursued. The individual views of doctors varied and added to patients’ confusions. One respondent regularly verified what he had been told by the doctor.

“Oh, accepting the cases in the British Pharmacopoeia there are always going to be extremes and you must read between the lines.” (27A)

**Illness pathway**

The sense of loss that resulted from the eventual deterioration in lung function was a constant cause of frustration for many, describing themselves as ‘just ended’ or ‘finished’. Breathlessness, lack of exercise capacity and the resulting disabilities experienced were a constant battle, resulting in basic tasks becoming slow and laborious.

“Although, I don’t think there is any point in carrying on for the last few years, feeling like I do.” (24A)

The hopelessness of the disease was sometimes based upon what they perceived as just having to ‘get on with it’. This view was partly supported by respondents’ memories on the initial diagnosis and the poor prognosis of ‘nothing to be done’. One respondent stated that patients with COPD were lucky to have benefited from ‘spin-offs’ as a result of the drive to care for patients with asthma. The relationship with their doctor appeared to be strengthened over time and illnesses, but particularly when a level of empathy was expressed.

“I certainly warmed to his comments and things he said to me straight away . . . and when he said to me I am a fellow sufferer I know . . .” (27A)

The range and level of daily illness crises experienced by patients placed a fine line between what the patient perceived as medical and social needs. Patients perceived health care needs as a direct intervention based upon a severe exacerbation rather than information giving, and believed that much of their informational needs would be viewed as ‘silly’ or using already stretched resources. However, five respondents were fearful of asking questions because they might not be able to cope with the answers.

“I mean it might frighten me to death.” (19A)

Social needs centred on mobility issues, coping with bouts of breathlessness in a social context, and worries about differing environments exacerbating their symptoms. These issues combined with a view that the public is largely ignorant or disdainful of this ‘self-inflicted’ disease made some respondents anxious about outings.

“There are those who see an elderly man, breathless, and they immediately assume that he is senile.” (9A)

Social care needs such as washing and dressing in the morning were exhausting and required frequent breaks to recover from bouts of breathlessness for all but two respondents. Their loss of exercise tolerance was something they felt they had to adjust to and that there was no point in wasting the doctors’ time as there was ‘nothing to be done’. This left them with less and less time and energy to undertake more interesting activities. Two
respondents had purchased exercise equipment to offset their loss of exercise and muscle wasting. Having purchased the equipment, their perceived need for supervision held them back from attempting to carry out any exercises. Other issues mentioned were based upon basic information to help understand their diagnosis, advice and training in administering their inhalers or asking what their doctors saw as a ‘credible’ reason for being called out when they felt ill.

Many respondents went to great lengths to plan their outings in an attempt to appear ‘normal’ and ensure that ‘panic attacks’ were kept to a minimum. As a result, they became increasingly socially isolated. One respondent was so sensitive to the risk of coughing up phlegm whilst out that outings were kept to a minimum.

“If I thought I might cough I wouldn’t go.” (18A)

Respondents who had poor family support and lived on their own were the most vulnerable.

“I thought I can’t keep ringing up my nephew, I can’t keep on. So I used to stay up there and suffer by myself.” (21A)

These social restrictions were not discussed with their doctor. The self-inflicted nature of their disease, compounded by the public’s poor understanding of the disease were additional factors in their social isolation. Some felt they were the poor relation to asthma. This was based upon the media interest and health centres holding asthma clinics. Some respondents were more pragmatic and expected little understanding from the general public.

**Medications**

Four patients were secretly stockpiling antibiotics and steroids. Six participants had stocks of antibiotics or steroids supplied by the doctor. Four participants stated that they had built up their own supply by shortening their prescribed courses of treatment.

“I try and control it. I generally get antibiotics in store.” (13A)

“I have the cure at hand, I don’t have to go bothering the doctor and making a nuisance of myself.” (16A)

There was a note of resignation in the voice of one respondent who had initially expressed an interest in managing antibiotics and steroids to the doctor.

“Well, I thought then I did . . . but since it has been explained that it wasn’t very wise to keep them, and, I suppose if you were getting relief from them you would use them too often.” (26A)

One respondent having been declined the opportunity to take antibiotics and steroids away whilst on holiday was amazed to see the vast array of medications that could be bought over the counter in Spain.

The three participants who did not wish to manage their own antibiotics and steroids tended towards emotion-focused attitudes. This respondent frequently failed to seek help when ill and recently had had two emergency admissions.

“Well that is what I mean it just didn’t seem . . . I just thought oh well, I just didn’t bother.” (21A)

Comprehension and compliance with medications also appeared to be an area of uncertainty for the emotion-focused responder.

“Not so much I realise I haven’t taken it, (inhaler) I realise I must have it again, I must have another one.” (24A).

Steroids were a major source of anxiety for 11 respondents. Much of the information they had retained was through hearsay or the media. Their concerns had not been expressed to any member of the health care team, chiefly as they did not want to be thought of as silly. One respondent constantly studied her face in the mirror for the ‘moon face’, another had only read of the use of steroids for sex changes and had been philosophical about the possible changes.

“I have since learnt that there are different kinds of steroids for different problems. So, obviously they are not going to turn around and say oh! He has got emphysema, we will make a woman out of him!” (22A)

**Power in the doctor–patient relationship**

The sense of power that health care professionals held over this group of patients was best shown by what the patients chose not to discuss during their consultations. A significant cause for concern with respondents was the need to be a ‘good patient’ and not a ‘nuisance’.

“They would possibly come during the day, depending upon what time, but as I say if it happened during the night, I don’t know.” (14A)

“My daughter asked for him. I didn’t ask for him, she sent for him.” (26A)

One patient failed to divulge continuing smoking habits for fear of being struck off the list. For two respondents, reluctance to seek advice from their doctor regarding lung transplantation or reduction surgery continued for months, even though they had requested written information from specialist centres undertaking research programmes.

The wish to gain some control over their disease was reflected in the need to purchase their own equipment such as nebulizers, having used them in the health centre for attacks of breathlessness. Three patients admitted purchasing a nebulizer of their own volition, partly due to the difficulties in gaining easy access to nebulizer
therapy. This gave them a prop in time of panic, citing the intense fear that attacks of breathlessness gave them. One patient purchased a large and heavy nebulizer from the second-hand section of a newspaper. For some patients, this has resulted in tensions with their doctor when nebulizer therapy had not been discussed or prescribed previously, with one doctor on hearing of the purchase ‘throwing his hands up in horror’.

Discussion

Qualitative research illuminates complex psychosocial issues. The sample size in this study is small; however, in qualitative inquiry, the aim is adequately to answer the question in the area under investigation or present a new theoretical basis for further research.

The difficulties that COPD patients experienced both socially and psychologically in this study have been well documented elsewhere.\textsuperscript{8,27} This paper highlights the point that the COPD patients may be compromised not only by the need to be seen as a ‘good’ patient but also due to their limited ability to cope with their ever increasing breathlessness. The level of respiratory impairment in this study did not correlate with the patients’ ability to cope with their disease. The most vulnerable group in this study appeared to be respondents who lived alone with limited financial and social support. Disparity between the degree of respiratory impairment and the patients’ level of functioning or quality of life has also been demonstrated.\textsuperscript{8,27} Dudley \textit{et al.}\textsuperscript{28} described COPD patients as being in an ‘emotional straitjacket’. This interpretation could have failed to recognize the patients’ perspective in issues such as breathlessness. GPs have been shown to be poor assessors of functional disability of their patients and fail to access other members of the primary health care team in the care of chronic disease patients.\textsuperscript{29}

The chronic disease patient searches for meaning, mastery and self-esteem to allow them to re-interpret their view of themselves as having value and a role in society.\textsuperscript{30,31} Potential uncertainties in diagnosis and physical assessment of the patient play a part in the difficulties of the doctor–patient relationship. However, the complex multidimensional components that affect the individuals’ perception of health and illness require careful appraisal. Some patients have a fear of the truth and may feel unable to cope with the facts of their diagnosis. Recent research into the informational needs of cancer patients identified similar views.\textsuperscript{32} Many ‘models’ of behaviour have been presented over the years. A wealth of literature attempts to identify social responses to illness, the individual’s own construction of health and illness as well as the complex behavioural factors that affect the patient’s ability to cope.\textsuperscript{33} These behavioural models have been used to help formulate a clearer understanding of the doctor–patient relationship, resistance to health promotion and treatment adherence.

It is now clear that issues such as adherence to treatment are linked to the individual’s satisfaction with the consultation process, as well as clear understanding and recall of information given.\textsuperscript{24} Until recently, scrutiny has been on the limitations of the patient in the consultation process and coping with their disease. However, there is increasing recognition that health care professionals, like anyone else, cannot be assumed to be consistent, and they bring their own agendas and subjective belief systems to the consultation.\textsuperscript{35} Patients’ behaviour during the consultation is often adapted to adjust to the doctor’s needs, and the use of effective psychological management is sometimes overestimated in general practice.\textsuperscript{35} Doctors are used to the process of the consultation, often have developed their own particular consulting style and usually have a clear agenda about what they wish to achieve throughout the process. Patients hold a wide range of expectations and preconceptions before the consultation but often fail to achieve their overall objectives in the consultation process.\textsuperscript{36}

Chronic disease patients are regular consumers of health care provision and, as such, become experts in assessing the interactions between themselves and their doctor although they may fail to express their observations openly. Our data suggest that a contributing factor in the patients’ failure to adhere to treatment or alter health behaviours may be based around their perceptions of their doctor. The limitations of the doctor–patient relationship may also be a contributing factor in failure of patients to seek early medical advice and subsequently requiring emergency admission to hospital.

The patients in this study perceived each exacerbation as a new life threat. The poor prognosis, steady deterioration and life-threatening sensation of breathlessness place this group of patients in a vulnerable position. Compounded with the often self-inflicted nature of COPD and the need to accept a chronic disease status, patients experience social, psychological and medical crises in their illness progression.\textsuperscript{12} Each crisis represents a downward spiral and a psychological re-appraisal and readjustment in their illness pathway. Hospital at home schemes have proved successful in improving care for patients with COPD and have the additional bonus that they encourage social factors to be considered in the overall needs of the patients.\textsuperscript{37}

Patients in this study perceived their doctors as holding immense power over any decision-making process that they believed might alter the course of their disease. As a result, they would go to great lengths to ensure that they were seen as a ‘good’ patient. The poor self-esteem, loss of hope and fear experienced by these patients reduces their ability to be assertive and seek the support they may need. Trying to identify a credible cause for seeking medical aid and uncertainties that anything could be achieved added to the daily stresses of illness
for these patients and the intensified feelings of loss of control; these findings are supported in earlier research.\textsuperscript{19,21,23} Patients often seek an appointment with their doctor when they have reached the limit of their tolerance in coping and often have views about what they wish to achieve from the consultation; failure to recognize this agenda may affect the patients’ perception of the value of the consultation.\textsuperscript{12}

A significant factor in improving the quality of life of COPD patients has been identified as the individual’s belief in the ability to control aspects of their lives.\textsuperscript{11} Despite these findings, current trends towards informing and empowering the patient are slow to present themselves in daily practice.\textsuperscript{19} The recognized need for shared decision making may become more of an imperative when issues of clinical risk and informed consent are combined with recent government agendas to empower the patient.\textsuperscript{25}

This study is based upon the patients’ perspective of living with COPD as remembered and interpreted by them. It has identified a central component, that of their relationship with their doctor. This relationship appears to have a significant consequence upon the patients’ quality of life and confidence in coping with their disease. Although doctors may believe that their relationship is on an equal basis with their patients, it is clear from this study that this is not the case.\textsuperscript{19}

There is increasing research evidence that recognizes the need for a more equal relationship between patients and health care.\textsuperscript{36} Developing a format for frank and open discussion would also provide the primary care team with greater insights into the individual patient’s ability to engage in appropriate coping strategies. The beneficial effects of this approach could result in improving the patient’s self-esteem and perceived control over their disease. However, it has to be recognized that some patients will wish to stay in a paternalistic relationship with their doctor.

The patients in this study did not view the primary care team nurses as a useful resource for them to call upon. Randomized controlled trials have demonstrated the value of nurses involved in the care of acute and chronic illnesses using a telephone follow-up service.\textsuperscript{22,39} It would be useful to explore whether easier access (possible via a help-line service) to the primary care nurses could reduce emergency admissions to hospital. NHS Direct was not functioning fully in this region at the time of the study, and it may be worthwhile researching the potential benefits of encouraging chronic disease patients to access the information available via this source.

Further research would be justified in examining the complex inter-relationship between doctor and patient, the resulting changes in health behaviours and the patients’ belief in their ability to manage exacerbations more effectively. Patients deserve and need to be full partners in the provision of their health care, not only because it is right but also because current health provision is unable to sustain the growing burden of increasing chronic disease without the active participation of the patient.\textsuperscript{9}

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