The needs of patients dying of chronic obstructive pulmonary disease in the community

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Background. Ninety percent of the last year of life of a terminally ill patient is spent at home, but possible drawbacks to domiciliary terminal care have been suggested. Most previous studies have taken place in secondary care settings, and have often obtained relatives’ views of patients’ needs rather than those of the patient.

Objectives. Our aim was to determine the needs of patients dying in primary care from chronic obstructive pulmonary disease (COPD).

Methods. Semi-structured interviews were undertaken with 16 patients who were having maximal therapy for COPD, who were thought likely to die in the year following the commencement of the study.

Results. Five themes were identified. (i) Patients’ information needs and the future course of their illnesses. Information needs were often variable and patients were sometimes unwilling to contemplate the future. (ii) The impact of symptoms on patients’ lives. Dyspnoea was a particular problem. (iii) Attitudes towards and opinions on smoking, which many acknowledged as being causal. (iv) Attitudes to help received. Many patients relied on their family; most patients felt their doctors were helpful although some expressed reservations. (v) Patients’ expressed needs. These usually focused on mobility, and many patients would not express needs even when prompted.

Conclusion. Poor symptom control remains an important cause of distress. The low number of expressed needs may reflect patients’ unwillingness to appear ungrateful, but the variability of information needs emphasizes the importance of an individual approach to patients with an apparently homogenous disease

Keywords. Dying, primary care.

Introduction

It has been estimated that 90% of the last year of a terminally ill patient’s life is spent at home,1 and most physicians believe that patients should spend more time there.2 There are, however, possible drawbacks to domiciliary care at the end of life, including poorer pain control2 and problems in communication between the patient and professionals.2 Fordham and Dowrick3 reviewed studies of the care of dying patients conducted between 1969 and 1999 and found that improvements in terminal care have been largely confined to patients in hospices, and to patients with malignant disease. Addington-Hall and colleagues4 in a national retrospective study found that one-sixth of non-cancer patients [including those with chronic obstructive pulmonary disease (COPD)] suffered above the median number of symptoms in the last year of life (compared with one-third of cancer patients), and Gore et al.,5 who directly compared patients with COPD and lung cancer, found that patients with COPD had significantly worse activities of daily living compared with those with lung cancer.

Much initial work about palliative care was concerned with the views of bereaved relatives, ascertained after the death of the patient, but, as Seale6 has emphasized, relatives “use research interviews to defend their moral reputations” and their views may not necessarily reflect those of the patient. Other more recent work has
been concerned to interview terminally ill patients themselves. For example, Skilbeck et al., who interviewed 63 patients with COPD, found a high level of reported physical symptoms with low social contact and low emotional well-being.

The aim of this study was to determine prospectively the needs of patients dying in primary care from non-malignant conditions. These are patients who would not normally be considered for hospice care. Pilot work in the research group suggested that most patients would suffer from cardiac or respiratory disease, and we therefore chose to interview patients dying of COPD for this study.

Methods

Research group members identified 16 patients from their own primary care practices in the North West of England (n = 7), who were having maximal therapy for COPD, which in the opinion of the GP involved was likely to result in death of the patient in the year following the commencement of the study. Patients with dementia or who were otherwise unable to take part in an interview were excluded, as were patients who could not be interviewed in English. This resulted in all patients being white (some 10% of patients in Bolton are of non-white origin, but amongst the elderly English is often not spoken). Consent for interview was obtained by the patient’s usual doctor, who explained the interview as research into the needs of seriously ill patients. Local Research Ethical Committee approval was obtained for the study and consent was obtained by the interviewer at the time of interview. A trained, non-medical, interviewer conducted the interviews. Patients were reassured that criticism of their care would not be relayed to their doctors unless they wished this to happen. Patients were interviewed alone in their own homes, without the presence of relatives (except in one case where this proved impossible).

The interview schedule was semi-structured and was derived from previous work and clinical experience (see Appendix). The interviewer was instructed to encourage the patient to diverge from the schedule when possible, and the schedule was modified during the course of the research (see below). Interviews lasted from ~45 to 90 min, and were tape-recorded and transcribed. All transcripts were read by two members of the research team (IJ and PO) apart from those of two respondents who were patients of one of the researchers. Early transcripts were checked for accuracy against the tape-recordings. Each researcher independently identified themes emerging from the interviews and, after the first five interviews, the Research Group met to consider initial themes; one new theme was identified (attitudes to smoking) which was introduced into all subsequent interviews. Transcripts were analysed by charting and thematic analysis during the study period, and after 16 patients had been interviewed the researchers felt that no new themes were being identified; the study was halted at this point. The expected deaths of patients prevented us from checking our data with respondents, and it was not felt appropriate to interview relatives in this study.

Results

The age range of the patients was 62–83 years with a mean age of 74.1 years; eight patients out of 16 were female. The study was carried out in the first half of 2002.

Five themes emerged from analysis of the interviews. They were: (i) patients’ information needs and the future course of their illnesses; (ii) the impact of symptoms on patients’ lives; (iii) attitudes towards and opinions on smoking; (iv) attitudes to help received; and (v) patients’ expressed needs.

Letters and numbers in square brackets below are patient identifying letters and transcript page numbers.

Patients’ information needs and the future course of their illnesses

Most patients knew the name of their illness, either from the hospital or their GP. Half wanted further information, sometimes for managing their lives:

Interviewer: “What information would you like to have?”

Patient: “How long I’ve got to live, well how long I’m still likely to last and how it deteriorates you know what I mean because at first when I first got it, doctor said that she couldn’t believe how much I deteriorated in 12 months, so I can’t, well what do you do, so you know it’s just that I’m interested, not that I’m worried just that I’d like to know what’s happening to me.” [D20]

However, half did not—either feeling that further information would not help, or through fear of what that information might be:

“No, what I know is enough for me. I know it won’t go any better, it’ll go worse if anything.” [H14]

Some patients were clearly ambivalent, and felt that doctors should be able to vary their responses according to the patient’s needs:

Interviewer: “Would you want somebody to discuss what’s likely to happen with your disease, you know, you said you don’t know what’s going to happen, would you want to know?”

Patient: “Sometimes I would, sometimes I wouldn’t. When I’m feeling alright I feel great and I don’t care but . . .” (patient does not finish sentence) [K8]
Over half knew their condition was progressive or incurable:

“If it (the illness) carries on deteriorating at the rate it has done over the last couple of months then I can’t see much future beyond that.” [N11]

However, one patient felt he would live for years. A small number felt that the progress of the illness was determined by individual effort:

“I mean that it will progress, it will go worse but depending on the individual as to what you do, if you exercise your lungs I think that helps.” [A12]

Two patients felt that the future was unpredictable, some said they might not get better after the next exacerbation, and a quarter were unwilling to contemplate the future:

“Well, I suppose people think I should know a bit more about what I’ve got and that but I just don’t want to dwell on anything like that.” [H15]

Impact of symptoms on patients’ lives
Breathlessness predominated, with the consequent lack of mobility that many patients found frustrating and which contributed to difficulties around the house and with social contact:

“And like I say I used to get out two or three times a week you know seeing my friends across the road at the British Legion.” [D2]

Anorexia and difficulties eating affected a quarter of patients, with backache and poor sleep also mentioned by a quarter. Other physical symptoms were infrequent, but anxieties were common, with more than half the patients expressing a fear of being or becoming a burden on their carers:

“Well for one thing, its my wife’s health that I am bothered about.”

Interviewer: “Tell me what bothers you about your wife’s health.”

Patient: “Well I mean in the night she’s up out of bed to see that I’m all right, if she can’t hear me she’s out, you see we sleep in separate single beds like you know through the illness really and erm, she’s tending me during the night, she’s, like in the morning she will come, she gets up, she er, brings me my painkillers whatever and a cup of tea like that, other than that she’s helping me to dress.” [F17]

An overt fear of dying was only expressed by a quarter of patients, with particular fears of dying alone:

“I worry in the middle of the night if I can’t get my breath I shall be on my own and die.” [G12]

A fear of cancer was only mentioned by one patient.

Attitudes towards and opinions on smoking
More than half of the patients felt that smoking had been a cause, partial or substantial, of their illness:

Interviewer: “How do you feel (smoking) has contributed to your present state of health?”
Patient: “Oh its 100 per cent contributed.” [L13]

This was a major issue for one patient:

Interviewer: “How do you feel about having been a smoker?”
Patient: “Oh terrible I do now; terrible. Now I’ve got what I’ve got, and knowing how easy it was to stop, I never tried to stop smoking you know I kept saying to myself for years and years and years, I’m going to cut them down, and I cut them down.” [I8]

Attitudes to help received
All patients felt that they knew when and how to seek help, although some preferred to leave the decision to seek help to relatives:

Interviewer: “Are you confident you know when is the right time to be looking for help?”
Patient: “My son is always here.”
Interviewer: “Would you know when to call the doctor?”
Patient: “My son would do.” [C12]

A majority felt that they could manage a relapse with appropriate assistance. More than half of the patients felt that their GP was a help, but a quarter felt that he might be too busy or had experienced other problems:

“I think with this sort of thing you should be on an automatic visiting list, not constantly having to ring them up to come.” [N15]

Similarly, a quarter felt that hospital admission had contributed to their problems, mainly by giving them infections. Few mentioned the primary care team or its members apart from doctors.

Expressed needs
The lack of social contact was a problem for a few patients (but explicitly not for one patient, who did not want to talk to others). Of those patients expressing needs, most focused on mobility, with the lack of a stair lift or wheelchair mentioned. Few patients felt that further input from the primary care team was either necessary or realistic; most were grateful for their nebulizers and oxygen, with few believing that further medication would help.

Many patients would not admit to needs, even when prompted to think of psychological and physical problems:

Interviewer: “What about a shoulder to cry on, you know somebody to have a good moan to, do you need that?”
Discussion

The main themes identified are those of poor control of symptoms, the burden these patients felt they placed on their carers and the need for further knowledge about their illness.

That this group of patients identified poor symptom control as a major issue is unsurprising, as helping them is a difficult task, particularly with dyspnoea. This accords with Skilbeck’s findings and, in view of some patients’ reluctance to express needs, emphasizes the importance of seeking symptoms in this group of patients. This study also revealed a concern felt by patients about the burden they placed on those relatives involved in their care. This may explain the lower level of unmet needs expressed by our patients compared with those expressed by relatives in previous studies, since patients may be reluctant to seem ungrateful for the care that they do already receive, even when they are being interviewed alone.

The interviews revealed two distinct patterns with regard to knowledge of their illness, which accords with Gore’s work. Some patients felt they would benefit from more information especially with regard to the course of their illness, while others were happy with their current level of information and expressed no wish to know what the future might hold. Murray et al. found that most patients with heart failure “do not understand the cause or prognosis of their disease”, but this did not seem to be the case for patients with COPD, which suggests that patients with different illnesses may have different information needs.

Two factors may limit the generalizability of this study. First, our patients were selected by their own GP to take part in the research, and this probably implies a good doctor–patient relationship for the majority. Secondly, our study was restricted to a group of illnesses where it is particularly difficult to identify prospectively the patient who is dying, although in all cases the patient’s doctor felt that the patient was receiving palliative care.

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References


Appendix. Interview schedule

Impact of illness on patient’s life; how the illness has been handled and by whom.
Symptoms—open-ended but must cover dyspnoea, pain, appetite, continence.
Understanding of illness—what has patient been told about illness and treatment?
Anxieties—related to illness and non-illness worries.
Sources of help—non-medical and medical.
Smoking (added after five interviews)—attitudes to their own past and present behaviour.