

# GP discussion of prognosis with patients with severe chronic obstructive pulmonary disease: a qualitative study

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## SUMMARY

**Background:** Recent research shows that health professionals do not communicate about prognosis with patients with chronic obstructive pulmonary disease (COPD) as openly as with patients who have cancer.

**Aim:** To identify strategies that general practitioners (GPs) can use to facilitate discussion of prognosis with patients who have COPD.

**Design of study:** Telephone interviews of 15 GPs and five respiratory consultants on the topic of discussing prognosis with patients who have severe COPD.

**Setting:** Participating doctors worked in the Auckland region of New Zealand.

**Method:** GPs and consultants were selected purposively to detect unique and shared patterns from diversity in how prognosis is discussed with patients with severe COPD. An interview guide was developed from a literature review and results of our earlier postal survey of GPs. Transcripts of audiotaped interviews were analysed independently and then together by three authors, using a general inductive approach.

**Results:** Seven strategies were identified that GPs had used or could use to facilitate discussion of prognosis with patients with COPD. These were: be aware of implications of diagnosis; use uncertainty to ease discussion; build relationship with patients; be caring and respectful; begin discussion early in disease course; identify and use opportunities to discuss prognosis; and work as a team.

**Conclusion:** A number of suggested strategies can be used to facilitate discussion of prognosis with patients who have severe COPD.

**Keywords:** prognosis; access to information; advance directives; chronic obstructive pulmonary disease; truth disclosure.

## Introduction

WORLDWIDE estimates of the prevalence of chronic obstructive pulmonary disease (COPD) range from 4–6% of the adult population.<sup>1</sup> However, because of its indeterminate beginning and slow progression, the disease is likely to be underdiagnosed.<sup>2,3</sup> In New Zealand, COPD is the fourth leading cause of death (after cancer, heart disease, and stroke), and is responsible for approximately 1% of discharges from public hospitals and 1.5% of bed-days.<sup>4</sup> In 1997, its impact on the health of New Zealanders was the third highest overall, after ischaemic heart disease and stroke — second in men and fifth in women.<sup>4</sup> Mortality rates ascribed to COPD are about 5% of all deaths; those for the indigenous population of Maori are almost double those of non-Maori, and COPD mortality rates for Maori women in New Zealand are the highest reported for any known population of women worldwide.<sup>4</sup>

It is now generally agreed that a palliative care approach, as used routinely for life-challenging cancer, is equally valid for incurable chronic diseases such as COPD.<sup>5,6</sup> It is usually assumed that effective palliative care includes open communication between health professionals and patients, particularly in discussing end-of-life issues such as patient hopes and fears, place of death, and prognosis. However, it is uncertain that professionals communicate prognosis with patients who have COPD as openly as with patients who have cancer.<sup>7,8</sup> The National Institute for Clinical Excellence (NICE) Guideline for management of COPD 2004 discusses the issue of palliative care,<sup>9</sup> but neither the Australian and New Zealand guidelines for the management of COPD<sup>10</sup> nor the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guideline update<sup>11</sup> discusses the issue, except for a reference to the need for patient education to 'initiate discussions and understanding of advance directives and end-of-life issues'.<sup>11</sup> A worldwide review of 41 COPD guidelines that were published in the 1990s found only seven (17%) covering ethical issues, including advance directives, in severe COPD.<sup>1</sup>

Despite a heightened profile of COPD over the last decade, a study indicated that general practitioners (GPs) in the UK<sup>12</sup> still do not routinely discuss prognosis with patients who have COPD; a further unpublished study highlighted the same situation in New Zealand. In these studies, GPs defined the meaning of prognosis to include:

- what the future might look like (80% of GPs),
- how breathing might change over time (55% of GPs),
- how long until death (48% of GPs).

More than 70% of responders considered discussions about prognosis to be 'essential' or 'often necessary' in managing

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**HOW THIS FITS IN***What do we know?*

Despite general acceptance that a palliative care approach is appropriate for the primary care management of chronic obstructive pulmonary disease (COPD), recent research shows that health professionals do not communicate about prognosis with patients with COPD as openly as with patients with cancer. General practitioners (GPs) are the main medical provider of care to patients with COPD in the last year of life. COPD is one of the 10 chronic disease areas in the clinical domain of the quality and outcomes framework of the new GP contract in the United Kingdom.

*What does this paper add?*

This study identifies practical and effective strategies that GPs can use to facilitate discussion of prognosis with patients who have severe COPD.

COPD, and believed that 'GPs have an important role in discussing prognosis'. Yet, only 41% of the 214 London responders and 56% of the 284 responders from the Auckland region reported discussing prognosis 'often' or 'always' with patients with severe COPD. Both studies reported that a third of GPs experience difficulty in knowing which patients want to discuss their prognosis and how best to initiate these discussions; this finding may help to explain the discrepancy between what GPs say is important to do and what they actually do. As GPs care for most patients in the final stages of their illness,<sup>12</sup> we aimed to identify practical and effective strategies for GPs to facilitate discussion of prognosis with patients with severe COPD.

**Method****Sampling**

Between May and June 2003, 15 GPs and five respiratory consultants gave a telephone interview lasting from 15–20 minutes on the topic of discussing prognosis with regard to severe COPD. The GPs were purposively selected from a sample of 83 GPs who, as part of a postal survey of GPs in the Auckland region, had indicated 2 months previously that they would consider taking part in such an interview. This region accounts for almost a third of the national population and a quarter of all urban land cover in New Zealand and, compared with the rest of the country, has a disproportionately large number of residents who self-identify as non-European.<sup>13,14</sup>

To detect unique and shared patterns from the diversity of responses to the GP survey, we selected the GPs to cover three main groups: those reporting, respectively, that they usually, sometimes, or rarely discuss prognosis with patients who have severe COPD. We also sought a sex balance and an ethnic mix of GP participants.

To contribute a potentially different practitioner perspective, five respiratory physicians (RPs) were selected from three public hospitals in Auckland, including the sole referral centre for the prescription and supply of long-term oxygen therapy in the region. These consultants were selected on the basis of having a specialist interest in COPD. However, in contrast to the process of GP selection, we did not know in advance how frequently they discussed prognosis in severe COPD. Table 1

summarises the sample and allows responses to be linked to participant attributes.

**Interviews**

A personal interview guide was drawn up by three of the researchers after a literature search and analysis of preliminary results of the earlier postal survey of GPs. A question about the influence of 'culture' was introduced when its relevance to discussions about prognosis, quality of life, and family support and care emerged during the interviews. Supplementary Box 1 shows the questions posed with linked prompts.

All the interviews were conducted over the telephone by one of the authors; they lasted from 15–20 minutes and took place mostly while participating doctors were at their place of work in the Auckland area, which is predominantly urban and suburban. The interviewer sought to conduct the interviews in a non-judgmental manner and ask the same core set of questions of all participants using a semi-structured format. A journal was kept and updated immediately after each interview. All interviews were audiotaped and transcribed with participants' consent. Ethical approval was obtained from the University of Auckland Human Subjects Ethics Committee.

**Analysis**

Four authors independently read all the transcriptions several times. They used a general inductive approach to systematically reduce and reassemble the participants' narratives in order to identify salient themes. Through discussion, agreement was reached on a single set of themes; one author used NVivo software to connect and develop these into broader themes, or analytical categories, for use as a framework fitting all cases. Through peer review, this framework was then refined by the research team.

**Results**

This section describes seven strategies (the themes identified) for facilitating discussion of prognosis with patients who have COPD:

- be aware of implications of diagnosis,
- plan to use unavoidable uncertainty to ease discussion,
- build relationship with patients,
- be caring and respectful,
- begin discussion early in disease course,
- identify and use opportunities to discuss prognosis, and
- work as a team.

The strategies derive from participants' reports of what has 'worked' or 'not worked' for them in holding such discussions.

***Be aware of implications of diagnosis***

Participants indicated that discussions of prognosis first require increased awareness by GPs of the implications of a diagnosis of COPD. Two GPs who did not usually discuss prognosis — GP2 and GP8 — confirmed the view of RP1 that many doctors are unaware of the potentially terminal nature of COPD. These GP participants indicated that they themselves had not 'thought in those terms' about COPD. According to RP5:

Table 1. Participant attributes.

Participant	Frequency of discussion	Sex	Age group (years)	Ethnicity
RP1	Rarely	M	41–50	NZ European
RP2	Rarely	M	51–60	NZ European
GP1	Rarely	F	41–50	Maori/NZ European
GP2	Rarely	F	51–60	NZ European <sup>a</sup>
GP3	Rarely	M	41–50	NZ Indian
GP4	Rarely	M	41–50	Chinese
RP3	Sometimes	M	51–60	NZ European
RP4	Sometimes	F	41–50	NZ European
GP5	Sometimes	F	31–40	NZ European
GP6	Sometimes	F	31–40	NZ European
GP7	Sometimes	F	41–50	NZ European
GP8	Sometimes	F	41–50	Japanese
GP9	Sometimes	M	41–50	NZ European (not certain)
RP5	Usually	M	51–60	NZ European
GP10	Usually	F	41–50	NZ European
GP11	Usually	M	31–40	NZ European
GP12	Usually	M	41–50	South African
GP13	Usually	M	41–50	NZ European
GP14	Usually	M	41–50	Indian
GP15	Usually	M	51–60	NZ European

RP = respiratory physician. GP = general practitioner. NZ = New Zealand. <sup>a</sup> previous work experience in Tonga.

*'The prognosis of COPD and heart failure is intermediate; it is better than lung cancer but it is a lot worse than breast cancer, but that is not the perception of those patients. I'm not even sure that is the perception of most doctors.'*

A related issue was awareness of palliative care needs. GP9 said he had not applied the palliative care model to COPD, and acknowledged 'a disparity between the way we talk about prognosis and conditions [COPD and cancer] that probably have very similar prognoses'. GP7 also talked about the difference between the culture of cancer management and that of COPD, suggesting that this may have arisen 'because COPD has had a longer history and it has been approached as if we can treat it ...'

### Plan to use unavoidable uncertainty to ease discussion

GPs reported lacking confidence in discussing the prognosis of COPD because of the uncertain timeframe. As GP9 said, with 'COPD you go from crisis to crisis, and ... it is a little bit blurry where the end point is going to be.'

Several GPs indicated that they would feel more confident about discussing prognosis if they received specialist guidance about it. This was irrespective of how often they said they discussed prognosis. The four respiratory physicians who did not usually discuss prognosis also talked about difficulties associated with the uncertainty of the timeframe. Use of objective measures of function to assess disease severity was suggested to minimise uncertainty. However, three GPs used the unavoidable uncertainty of the COPD prognosis to palliate discussions of prognosis with patients.

### Build relationship with patients

A long-standing relationship with good rapport facilitates discussions about prognosis:

*'The better the rapport, the wider range of topics you can discuss in more honest detail and the more likely you are going to get them to ask questions as well.'* (GP15).

Most participants indicated their agreement, including GP13, who suggested that the quality of the relationship was of such importance that it could over-ride difficulties such as cultural differences:

*'My view is that it would be more to do with the doctor-patient relationship as to how these issues were discussed rather than the specific culture of myself or the patient I am dealing with and their background.'*

However, other GPs who usually discussed prognosis thought that language and cultural differences did pose barriers to effective communication about prognosis, especially for older patients in the absence of interpreters.

### Be caring and respectful

Several participants who sometimes or usually discussed prognosis spoke of how they did this by aiming to be as 'supportive and compassionate as possible' (GP7) and 'to be a friend' (GP12). Two participants discussed the importance of honesty in the doctor-patient relationship: GP15 commented that not to discuss prognosis is 'to be less than candid [and] kind of undermines the whole relationship of honesty', and RP3 spoke of a patient appreciating his 'frankness and honesty'.

Participants indicated the need not to imply that patients who smoked had brought COPD on themselves. RP3 noted that patients 'think that doctors are going to say to them, well, you deserve what you got ... so there is a lot of guilt and patients are often very defensive.' He concluded that it is counterproductive to attach blame.

Participants also spoke of the need to allay patients' fears by not overloading patients with negative details about how they might die, and offering reassurance where possible. Referring to statements made to patients, GP10 noted:

*'I say [that] generally people don't gasp their last breath, that many people die rather slowly but not of asphyxia, which is what their fear is'.*

GP9 attempted to be sensitive to feedback from patients:

*'I let them know I am happy to talk about it, and be honest with them, but if they need to be in the state of denial to cope, then I don't try to force them through that unnecessarily ...'*

RP4 observed that receptivity to discussions of prognosis seemed to vary between cultural groups, but concluded that: 'you can't assume anything, you check with the patient and see where they are at and what/how they want it dealt with.' Four of the five respiratory physicians noted that, in contrast

to New Zealand (NZ) Europeans, Pacific Islanders and, to a lesser extent, Maori patients often wanted to involve a family group in discussions of prognosis. Two respiratory physicians reported that in Pacific Island communities there was often someone in the family who spoke for the patient.

### *Begin discussion early in disease course*

GP15 emphasised that discussion of prognosis is not a one-off event. For example, GP15 said that it is 'part of discussing COPD regardless of whether they [patients] are [at] early, middle or late stage' and, 'I wouldn't wait until they're [at] end stage'.

Several GPs reported discussing prognosis as a component of patient education about things such as smoking. This enabled them to mention prognosis at an early stage after diagnosis. As noted by GP6:

*'If they were still smoking I would find it easier to initiate the whole consultation along the prognosis lines because I would tie it in to why it is important to stop ...'*

RP3 supported patient education and often uses the Fletcher and Peto diagram<sup>15</sup> to demonstrate that the rate of decline in lung function will slow if the patient stops smoking. RP4 emphasised the importance of beginning discussions early by saying that, 'it [discussion of prognosis] only goes badly if it is a shock or a surprise.'

### *Identify and use opportunities to discuss prognosis*

Participants who sometimes or usually discussed prognosis sought opportunities to do this, and responded to individual patient needs and wants regarding the extent of the discussion:

*'... [if patients] are given a lot of opportunities to [discuss prognosis], then they will do it if they want to ... [but] you try and judge where they are ... and how much they need to know.'* (RP4.)

Early in the course of the disease, the diagnosis and patient education afford opportunities for discussion of prognosis. Later, our participants tended to use events to trigger opportunities. GP13, for example, found that patients are usually receptive to discussions about their prognosis following an exacerbation; GP8 corroborated this:

*'... it arose in discussion of what we would do if she got another infection, and we talked about the fact that this wasn't an illness that was going to get better and was likely to deteriorate with time.'*

Other events that GPs had used to trigger conversations about prognosis were: a recent hospital admission or outpatient consultation with a respiratory physician; an observed deterioration in the patient's condition; a home visit; and an assessment of therapy options.

GPs also reported initiating discussion of prognosis in response to emotions, including the 'high levels of anxiety' of a patient and her daughter (GP5), and a realisation of how

'inappropriate' it was for a patient to be 'in the waiting room in a severely impaired and distressed state' (GP7).

Several participants used open-ended questions, such as: 'do you understand what we talked about? Are there any other questions?' and 'where do you think you are at?' to clarify patient requirements for information about prognosis. Two GPs commented that, not infrequently, patients asked about the prognosis, although it was also recognised that often patient queries were indirect and there was a need for the health professional to pick up on cues.

### *Work as a team*

As RP4 noted that, in guidelines for the management of COPD,<sup>4</sup> 'D is develop support networks' and GPs reported benefiting from the contributions of other team members. Two respiratory physicians suggested that discussion of prognosis is a collective responsibility, with RP5 stating: 'I don't assume the GP has done it and vice versa.'

However, teamwork also allows role differentiation and some participants highlighted the role of nurses. For example, RP5 said that practice nurses might be able to raise the issue of prognosis because of their strong rapport with patients and families. RP4 reported that there does not always appear to be a need to discuss the prognosis with patients:

*'... [if the COPD clinical nurse] has had a useful discussion with them [the patient] it may well seem an overkill for me to go in with them, but she will relay to me if she thinks that the patient really needs to hear from me.'*

GP3 mentioned that patients sometimes need to hear the prognosis from the consultant. However, GP10 suggested that a hospice nurse might be better at managing the fears of end-stage patients, because such nurses 'are used to dealing with the subject'.

Effective teamwork requires communication between team members about what has been discussed. RP3 believes that the wording of discussions, as well as the consistency of the content, is relevant to help avoid confusing patients:

*'It is important that both parties use the same terms and give the same sort of information ... [so] often when I am writing to the general practitioner I will outline what I discussed with the patient and will put in quotes some key phrases that I have used ... the same thing goes that they might tell me the phrases that they used.'*

However, GPs commented on the paucity of information from specialists regarding the discussion of prognosis:

*'No-one is ever sent a discharge letter or follow-up about prognosis and to my knowledge they have never discussed it with the patients'* (GP4.)

Likewise, some specialists commented on the lack of feedback from other health professionals; two participants mentioned dealing with this by asking patients what had been discussed. It was suggested by two RPs that using e-mail could improve and hasten communication between primary and secondary care about end-of-life discussions.

## Discussion

### Summary of main findings

Analysis of the interview transcripts yielded seven strategies that health professionals had used or could use to facilitate discussion of prognosis with patients who have COPD. These strategies included increased awareness that COPD can be a terminal illness, and the consequent need for a palliative care approach to the management of patients with severe COPD. Another strategy involved using unavoidable uncertainty to palliate discussions of prognosis. Responders said that good rapport facilitates discussions about prognosis; this includes being non-judgmental and finding out what information the patient wants. About half of the participants talked about the importance of openness and honesty.

Several GPs emphasised the importance of using patient education as an opportunity to initiate early discussion of prognosis. GPs who reported that they discussed prognosis relatively frequently tended to offer patients multiple opportunities to discuss prognosis, but were sensitive to patients' needs and wants regarding the amount of information given.

### Strengths and limitations of the study

How GPs and other health professionals can most easily discuss prognosis with patients with severe COPD is a neglected area of research. This study focused on this problem in an attempt to improve this area of disease management.

Participants self-reported whether they discussed prognosis 'rarely', 'sometimes', or 'usually'. These measures of frequency were not defined and so, individual doctors might have varied in the meanings they attached to each term.

Researchers' interpretation of interviews was not checked with participants. In addition, it should be noted that participants' self-reported behaviour might not accurately reflect their actual behaviour, and it was outside the scope of this study to elicit the perspectives of patients and their informal caregivers. Doctors are more likely than patients and caregivers to recall discussion of prognosis, yet the views of patients and caregivers are needed to evaluate the effectiveness of doctor communication when discussions about prognosis take place.

In an unpublished study by Mulcahy *et al* GPs were asked whether they agreed or disagreed that 'primary care is the right place to discuss prognosis in severe COPD'. Of those asked, 8% disagreed with the statement; the sampling strategy in this study did not purposively select any of those 8% of GPs. Hence, their perspective was not represented and GPs holding their opinion might question the relevance of the study aim.

A further limitation of this study is that no respiratory nurse specialists were interviewed. This is a significant omission as the number and role of respiratory nurse specialists working with patients with COPD is increasing, and is endorsed by the British Thoracic Society.

### Implications for clinical practice

The results highlight pragmatic strategies for use in general practice, which can help GPs, alongside other health professionals including respiratory physicians and specialist nurses, to think about how often and in what ways they discuss prognosis. These strategies indicate a need to develop clinical skills

specific to managing conditions such as COPD — for example, awareness of implications of the diagnosis with its uncertain timeframe — and interactional skills of a more generic nature, which can be applied to COPD. The latter skills are needed to implement strategies such as working as a team, with a role for specialists in guiding GPs on prognosis — not least because of specialists' generally increased detachment in defining the prognosis.<sup>17</sup>

All the strategies suggested can aid patient understanding, with early and ongoing discussion about the implications of a diagnosis of COPD.

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### Supplementary information

Additional information accompanies this paper at: <http://www.rcgp.org.uk/journal/index.asp>

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