They don't want it ramming down their throats. Learning from the perspectives of current and ex-smokers with smoking-related illness to improve communication in primary care: a qualitative study

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Aim: To enhance the effectiveness of smoking cessation communication in primary care by gaining insight into the motivations and perceptions of smokers and ex-smokers with chronic obstructive pulmonary disease (COPD). Background: Stopping smoking is the single most important action smokers with COPD can take to improve their health. A Cochrane systematic review identified the need for more research into effective smoking cessation approaches for patients with COPD. Methods: A qualitative study using semistructured interviews with COPD patients in South Yorkshire undertaken as part of the formal evaluation of an innovative rehabilitation program ('Breathing Space'). Participants: Patients with COPD (current and ex-smokers) who were invited to attend a program of rehabilitation or support at Breathing Space Findings: Current smokers tended to deny the contribution of smoking to their COPD. A low level of acknowledgement of the association between smoking and COPD was demonstrated, particularly by long-term COPD patients. Participants described health and money as the most important motivators in stopping smoking. An overly directive or ritualistic approach by health professionals was perceived as counter-productive. Participants perceived that smokers were deterred from accessing care through embarrassment and fear of discrimination. Conclusions: A direct but supportive approach is likely to be effective when discussing the association between smoking and COPD with patients. Assisting smokers to acknowledge the objective dangers and the personal risk of smoking is indicated. Approaching smoking as an objective condition to be solved as a joint enterprise between patient and clinician can reduce message avoidance while inducing a sense of personal control, thereby increasing successful quitting.

Key words: Breathing Space; COPD; motivation; patient and carer perceptions; qualitative research; smoking cessation

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Introduction

Smoking cessation is one of the most important contributors to improving the prognosis of patients

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with a chronic respiratory condition (Tonnesen et al., 2007) and the most important treatment for smokers with chronic obstructive pulmonary disease (COPD) (van der Meer et al., 2003). Health professionals therefore have a crucial role in motivating patients to make the decision to stop and then to provide the relevant treatment and support to do so.

While an increasing body of evidence assesses the effectiveness of smoking cessation interventions, the dilemma for many health professionals is what to say when confronted with a patient who shows no inclination to stop. This is particularly important when the patient has an established and progressive smoking related illness. The issue of patient motivation becomes more complex when stopping smoking may relieve symptoms but the underlying condition cannot be reversed, merely palliated.

NICE Guidance (2006) confirms longstanding recommendations that:

- doctors and other health professionals should use every opportunity to advise smokers to quit whenever they attend a consultation.
- smokers presenting with a smoking related disease should be given cessation advice linked to their medical condition where appropriate.
- the smoking status of those not ready to quit should be recorded and reviewed with the patient on at least an annual basis.

However, studies highlight the concern of clinicians in repeatedly advising long-term smokers to stop (Rollnick et al., 1997). Research suggests that general practitioners (GPs) feel uncomfortable about undertaking this task, and lack strategies for motivating smokers to quit (Coleman et al., 2004). Primary care clinicians express doubts about their own efficacy and about the capacity of patients to change (Rollnick et al., 1997; Coleman, 2004) while experiencing concern about compromising the doctor-patient relationship (Coleman et al., 2000).

Health professionals can find their role frustrating; giving information about the damaging effects of smoking is seen to be redundant as smokers are generally aware that smoking is dangerous to health even if they do not understand the magnitude of the health risk (Strecher et al., 1995; Smith et al., 2001).

Studies on patient perspectives indicate that repeated interventions by doctors deter patients from seeking help, and that a dictatorial approach is unwelcome (Butler et al., 1998). Reduced access to healthcare can occur when smokers fear victim-blaming (Richards et al., 2003) by health professionals and can be compounded by discomfort arising from self-blame, or feelings of annoyance when their smoking status is raised by doctors (Butler et al., 1998). Smoking cessation

advice can have the opposite effect to that intended if it is delivered without some thought to the individual (Irvine et al., 1999). Smokers tend to underestimate personal risk as a result of smoking, while experiencing internal emotional discomfort ('cognitive dissonance') as a result of knowing their health condition is aggravated by smoking (Chapman et al., 1993). Smokers do not translate the objective risks to the subjective. Weinstein (1999) describes this as 'optimistic bias' whereby smokers see their own risk as lower than that for other smokers (Arnett, 2000). The presence of 'self-exempting beliefs' (Chapman et al., 1993), denial and even fatalism - 'the damage has been done' - (Kerr *et al.*, 2006) in older smokers are further potential barriers in the decision making process to stop smoking and may further reduce the impact of clinician

There may be a tendency by those with COPD to deny, or at least avoid thinking about, the link between their smoking and their condition and attribute it to other causes, such as occupation or family history (Booker, 2005; Hansen et al., 2007). However, Hansen et al. (2007) suggest that the recognition that their illness is smoking related is an important factor in encouraging smokers to give up.

Despite the importance of smoking cessation in the treatment of COPD in smokers, a Cochrane collaboration systematic review (van der Meer et al., 2003) found that little is known about effective smoking cessation interventions for this patient group. There has been much research about effective smoking cessation strategies for 'healthy smokers', but the review concludes that more research is needed to determine what sorts of intervention would be most effective for different types of patient (van der Meer et al., 2003). This study is therefore intended to be developmental and gather data to help inform the content of tailored interventions that could be developed and tested in future work. As such, it investigates the perceptions of patients with COPD about the association between smoking and their illness. The study also examines their experiences of and attitudes toward health professionals who raise the issue of their patients' smoking status and encourage the decision to make a quit

Methods

Perceptions of the experience of living with a chronic illness are complex phenomena and not amenable to numeric or quantitative assessment. Qualitative methods comprising semi-structured interviews were therefore selected as most appropriate for generating multi-dimensional data from smokers and ex-smokers with COPD (Walker, 1985). The topic guide was designed for the interviews in consultation with the Breathing Space Research and Evaluation Advisory Group (which included patient and carer representatives and clinicians) to enable in-depth study of the experiences and perceptions of people living with COPD.

Selection of participants

In Rotherham, 5841 people have been identified from general practice records as having COPD. As part of the Breathing Space evaluation, the clinical audit department of Rotherham Primary Care Trust (PCT) conducted a quality of life survey in April 2007 of 857 patients for whom resource utilisation data were available. Completed questionnaires were received from 388 respondents. Respondents were asked to indicate on the questionnaire if they would be happy to be contacted by a researcher to be interviewed and, if so, to provide their telephone number. By the end of April 2007, 219 respondents agreed to be contacted and 11 of these were purposively selected to include a range of smokers and non-

smokers, severity of illness, age, gender and geographical location.

Interviews

One interview was abandoned before starting because the patient was too unwell to participate. Ten patients were interviewed between April and May 2007 (Table 1). Interviews were conducted in the patients' homes by the first author, with one interview taking place in Rotherham PCT head-quarters. The duration of the interviews ranged from 45 to 90 min.

The interviews were semi-structured, with questions being asked according to the topic guide from the research protocol. All interviews were tape recorded with the participant's permission, and later transcribed verbatim. Tapes and transcripts were anonymised. Information leaflets were posted to participants at least two days prior to their interview to ensure they had time to read them before providing informed consent on the day of the interview.

Analysis

Transcripts were read and re-read by both authors. Coding into themes and sub-categories was done using the constant comparative method drawing on the principles of grounded theory (Glaser and Strauss, 1967). Thus the topic guide (summarised in Figure 1) was amended as the interviews progressed and new themes emerged and required exploration. The first two interviews

Table 1 Details of participants

Identifier	Gender	Age	COPD severity	Smoking status: current/ex	Ex-smokers	
					Length of time stopped	Approximate number years as smoker
Pt A	М	66	Moderate	Ex	4 years	50
Pt B	M	75	Severe	Ex	10 months	65
Pt C	M	66	Severe	Ex	'A few years'	50
Pt D	F	62	Severe	Ex	3 years	40
Pt E	F	52	Severe	Ex	10 years	20
Pt F	F	56	Mild	Current	N/A	> 30
Pt G	M	73	Severe	Current	N/A	> 50
Pt H	F	42	Mild (moderate)	Current	N/A	> 20
Pt I	F	70	Moderate	Current	N/A	> 50
Pt J	M	78	Mild	Ex	26 years	> 30

Pt = patient; M = male; F = female; N/A = not applicable.

Perceptions of

- > The link between smoking and COPD
- > Motivations for stopping, continuing or re-starting smoking
- Support from health professionals

Figure 1 Topic area summary

served to pilot the topic guide and were included in the analysis. Each transcript was independently coded by the two authors to strengthen consistency in coding and the identification of developing themes. Coding was done manually using alphanumeric codes to denote thematic areas and sub-categories. The data were then analysed for agreement and variation and developed into the themes described in the results.

Results

Patient perceptions of the contribution of smoking to respiratory disease

While some respondents accepted the contribution of smoking to their condition, others saw little or no association between their health and their smoking history. Patients who accepted the effects of smoking described it as self-inflicted and expressed feelings of self-blame, embarrassment and regret in contrast to those rejecting the association who expressed denial and avoidance.

Self-blame, embarrassment and regret was generally expressed by the ex-smokers:

- It is self inflicted ... I accept that totally. (Patient A, ex-smoker)
- (B)efore I stopped smoking I wouldn't go to see my GP much... because I was embarrassed because I smoked. (Patient D, ex-smoker)
- (I)f I'd have known 50 year ago when everything was going right, I wouldn't have even have started. (Patient C, ex-smoker)

Conversely, denial was generally expressed by current or recent ex-smokers:

• I have been smoking all them years and I still don't think that had much effect on me actual *lungs...(Patient B, ex-smoker)*

• I know it has an impact on me COPD...But that to me weren't the primary cause. (Patient H, *current smoker*)

Self-conscious denial was expressed by one current smoker:

• I've never sat and thought about it actually.. If I had I wouldn't smoke would I? (Patient I, *current smoker*)

Unwillingness to confront smoking as a key factor in their disease was demonstrated by current smokers and reluctant ex-smokers such as Patient B, seriously debilitated by his severe disease, who had only recently stopped smoking after more than 60 years. Unlike other smokers who had successfully given up, he did not express pleasure or pride in having stopped smoking, but described it regretfully as a necessity brought on by his lungs no longer being able to cope with cigarette smoke. He attributed the underlying damage to his lungs to industrial exposure rather than his 65 year smoking history.

Motivation for stopping smoking

Two primary motivational factors for stopping and remaining non-smoking were identified: these were a) health and b) personal financial circumstances.

Participants described acute deterioration of their health as the trigger for a spontaneous attempt to stop smoking.

- My chest, I just can't take it now. (Patient B, exsmoker)
- I lit a cigarette up, took one puff. I just started choking and I said 'that's it I can't smoke any more'. (Patient E, ex-smoker)
- Well it frightened me, that's why I went on that course to stop smoking. (Patient F, current smoker)

Some participants described the benefit of having more disposable income to spend on items such as holidays as highly motivating.

• Well we couldn't have got abroad, we couldn't have gone on us holidays, if we'd have both *smoked.* (Patient J, ex-smoker)

However, in the case of ex-smokers, financial benefit as a motivating factor is by definition

post-hoc, so it is unclear whether the financial situation was the primary motivating factor in a successful quit attempt, or whether it is a major reason why ex-smokers are pleased to have successfully given up.

Respondents reported relative ease in stopping smoking while they were hospital inpatients, but invariably started again after discharge. Unlike motivational factors, the effects of this circumstantial trigger to stop smoking disappeared when patients returned to their own homes where they resumed habits historically associated with being at home:

- When I went into hospital, cigarettes didn't bother me one iota ... But as soon as I came out I wanted to light up. (Patient B, ex-smoker)
- When I were in hospital ... I didn't smoke for them three weeks 'cos I weren't allowed to. (Patient F, current smoker)

All ex-smokers described feeling physically worse after stopping smoking due, for example, to a worse cough or to weight gain. A patient who had stopped smoking for eight weeks after attending a stop smoking group found that feeling less well undermined the message that it was healthier to stop smoking. Those who succeeded despite the initial worsening of symptoms suggested it was due to their strength of resolve, particularly following a 'health shock'. Smokers attributed restarting to specific stresses in their lives such as a close bereavement.

All respondents were clear that any decision to stop smoking had to come from the individual concerned.

Perceptions of professionals and advice to stop smoking

Respondents emphasised that people cannot be coerced to stop. An overly directive approach on the part of health workers was seen to be counter productive.

- Well initially I think it's up to the individual every time. (Patient B, ex-smoker)
- I don't like... anybody telling me what I should do, it's got to be my decision. (Patient D, exsmoker)

There was a perception that people do not continue to smoke through a lack of knowledge

about the dangers of smoking so constant reinforcement of that message is unwelcome:

• They [smokers] know what the dangers are and they don't want it ramming down their throats, they want support, they want help. (Patient H, current smoker)

However, a doctor's forthright approach led one participant to stop smoking:

• [H]e says 'If you keep on smoking, do not bother coming back to see me'...And I was that upset, a doctor telling me I could not go back to see him, I were mad...I thought... 'Well that bloke must really think that smoking is going to kill me'. I never touched another fag from that day to this. (Patient J, ex-smoker)

External control

Some participants who continued to smoke expressed anger at being told what to do by health professionals, and resented their actions being dictated by someone else.

 People do not respond to 'thou shalt', they respond more to 'don't you think you ought?' (Patient G, current smoker)

These participants can be contrasted with others who described how they had disliked being controlled by their addiction to the chemical nicotine. Control was seen as being regained by patients who had successfully beaten their addiction.

- I'm back in charge of my own life... I am not being controlled by a weed. (Patient A, ex-smoker)
- Saying you're hooked, now to me that's more effective than trying to frighten someone to give up with that middle aged woman gasping for breath or them lung cancer things... but that is really effective, the latest (TV advertisement), because it shows... you really are hooked. (Patient D, ex-smoker)

However, resentment and antagonism towards the perceived attempts at external control by health professionals was expressed more forcefully than antipathy to the action of the chemical nicotine, externally controlling smokers through their addiction to tobacco.

Discussion

The findings described here support earlier qualitative studies in reflecting patients' differing

perceptions of the contribution of smoking to COPD (Booker, 2005). Participants demonstrated defensiveness and denial about the part smoking played in their illness, preferring to attribute their condition to occupational causes. Others who expressed regret described their condition as selfinflicted. None of the participants wanted to be instructed to stop smoking by a clinician, but expressed a desire to be in control of their decision. Smokers perceived themselves as receiving a reduced level of service. They believed this was because of the attitudes of health professionals or because smokers were reluctant to access services due to embarrassment or fear of being judged.

Personalising information

An acceptance of how smoking contributes to their illness appears to be important in encouraging smokers to give up (Hansen et al., 2007). Participants who most vigorously denied the effect of smoking on their condition remained smokers or reluctant ex-smokers. Personalising information to the individual could help to avoid the rejection of the perceived dictatorial advice that can alienate patients. It can be difficult for clinicians explicitly to personalise information, which involves saying things people do not want to hear. However, it has been suggested that clinicians should ask personalised questions designed to engender an emotional response in order to help someone gain insight into their own condition and generate a more receptive stance to smoking cessation (Prochaska and Goldstein, 1991). Findings from this study support the value of such an approach in recognising that smokers who refuse to acknowledge personal risk will avoid discussion compelling them to reassess their smoking status. Those who had reflected on their own condition spontaneously recognised the benefits to themselves of ceasing to smoke, and simultaneously felt in control of their own lives. Thus, while they valued smoking cessation support once they had made the decision to quit, exsmokers tended not to attribute their decision to the input of a health professional.

Directive versus non-directive approach

The main triggers for smoking cessation for the participants in this study were identified as acute health deterioration and potential financial benefit. There was universal agreement that the decision to stop smoking must come from the individual. This contrasts with findings by Schofield et al. (2007), which suggest that patients' decisions to quit were in response to external sources. West and Sohal (2006) suggest that attempts to stop smoking are more successful if the quit attempt starts immediately following a 'catastrophic' or acute health event rather than if the acute event leads only to a decision to make a quit attempt in the future. The experiences of patients in this study support this. Patient F experienced a sudden acute episode, which led to her deciding to attend a stop smoking group in the near future, but her quit attempt only lasted a few weeks. Conversely, Patient E, who threw away her cigarettes immediately after experiencing an acute episode, has not returned to smoking in the 10 years since then. These accounts indicate the importance of personalised approaches and adapting these to the circumstances at the time. The general advice of the National Health Service (NHS) smoking cessation service is to plan a quit day in the future, and the NHS Stop Smoking website states that planned attempts to stop smoking are most likely to succeed. However, health professionals working with people who have established smoking related disease, and as such are likely to have acute episodes, may wish to utilise the window of opportunity thus presented in supporting people to stop smoking immediately.

Participants expressed their dislike of a highly directive approach and some reported that this provoked anger or deterred them from accessing health services, demonstrating the possible perverse effect of unwelcome, routine smoking cessation advice seen in an earlier study (Irvine et al., 1999).

A balance between acknowledging the objective addiction to nicotine and translating this to the personal harm to the individual caused by smoking is indicated. While not alienating patients, it is important to help them to accept the damage smoking inflicts on their health, remembering that smokers will readily acknowledge the objective dangers of smoking (Chapman et al., 1993; Arnett, 2000), but resist applying the knowledge to themselves. Participants described their own health as crucial to the decision to quit, which was often spontaneous. Clinicians could put aside the fear of damaging the clinician-patient relationship and allow a personalised but honest

and collaborative approach, which may in fact strengthen the relationship while encouraging the patient to make their own decision. However, while there are well developed behavioral change models (Prochaska and Velicer, 1997) underpinning expert smoking cessation professional input, clinicians working in primary care need to have a pragmatic approach to encouraging and supporting someone to stop smoking, while maintaining a therapeutic relationship that may continue over many years. While ex-smokers' post-hoc views of why they stopped smoking may be distorted by time and may not harmonise with accepted theoretical models, it is important that the experience of receiving professional smoking cessation intervention is not a negative one, which undermines the future therapeutic, educational and supportive value of the clinician-patient relationship. GPs may advise patients to give up smoking one year and the next may be caring for them as they die of a smoking related illness. This illustrates the sensitivity of the relationship and the importance of adopting a thoughtful and sensitive approach to supporting someone to make the decision to stop smoking, but does not mean that the difficult issue can be avoided. Failing to address a person's smoking status contravenes guidance and accepted good practice.

Joint enterprise

In avoiding the directive role, alternative approaches could be considered. Arriving at a joint acknowledgement of the harm caused by nicotine addiction, asking 'how can we address this together?' might be productive. It could be presented as a joint enterprise to be undertaken by clinician and patient. This would enable control to be retained by the patient, which has been shown to be important while providing appropriate support and encouragement. Such an approach may help to avoid negative perceptions whereby smokers feel discriminated against for being smokers or highly embarrassed and so reluctant to access healthcare.

Limitations of the study and recommendations for future research

It was useful to take a sample from a large number of COPD patients and find out more about the perceptions and experiences of smokers

However, caution should be exercised as the participants were drawn from a confined and socio-economically similar geographical area. A more complete picture might further have been achieved if health professionals had been interviewed. Including these would be helpful in future research. The numbers of patients interviewed was small (four smokers and six ex-smokers). Although the researchers identified no major new themes emerging by the time of the final interviews, it may be considered that there can not be full confidence that data saturation was achieved given the numbers involved. However, as a developmental paper, it is suggested that the findings do have potential relevance and importance for informing future studies.

and ex-smokers with a smoking related illness.

Conclusion: implications for policy and practice

Doctors are seen to have 'immense power over patients' lives' (Oliver, 2001) and this study confirms the importance of patients feeling in control of the decision-making process. The importance of open frank communication in all aspects of COPD care is emphasised by Oliver and this perhaps applies to the crucial area of smoking cessation more than any other. The perceived counter-productiveness and dislike by study participants of perceived ritualistic and directive advice by clinicians has been discussed earlier. Eva et al. (2009) have recently confirmed previous conclusions that the major part of clinicianpatient consultations (irrespective of profession) involves eliciting information about the patient's history, with far less involvement of the patient's own ideas or fears; the end result often being focused on action rather than shared understanding and patient responsibility. Primary care clinicians may usefully consider the structure and approach to their consultations with patients, and this may be a fruitful area for designing interventions for future research. The participants in this study preferred to experience an internal locus of control (Stuart et al., 1994) and their perception of where the external controller lies was influenced by whether or not they had succeeded in giving up. It may be fruitful for health professionals to utilise this aspect of patient attitudes

toward the locus of control by encouraging smokers to perceive nicotine as the external locus of control rather than the clinician. Approaching smoking as an objective condition to be solved as a joint enterprise between patient and clinician can reduce message avoidance and induce a sense of personal control.

Declarations

Ethics approval was obtained (LREC Ref. 06/ O2306/24). The authors declared that this study is not under consideration by any other journal.

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