Original Scientific Paper

Patient and clinician perceptions of asthma education and management in resistant asthma:

A qualitative study

Sarah G Dean, Vanessa Young, C Raina Elley and Anne Bruton

Correspondence to: sarah.dean@otago.ac.nz

***Sarah Dean** is a senior lecturer in Rehabilitation at the School of Medicine and Health Sciences, Wellington, University of Otago; her background is in health psychology and physiotherapy.*

***Vanessa Young** is a medical student at the School of Medicine and Health Sciences, Wellington, University of Otago.*

***Raina Elley** is a general practitioner in South Auckland and senior lecturer at the Department of General Practice and Primary Health Care, University of Auckland.*

***Anne Bruton** is reader in Respiratory Rehabilitation at the School of Health Professions and Rehabilitation Sciences, University of Southampton, UK. Her research specialises in rehabilitation and management of chronic respiratory conditions.*

ABSTRACT

This study explores patient and health professional perceptions of asthma education and management in a lower socioeconomic general practice, using semi-structured interviews. Perceptions of Maori patients were emphasised, due to disparity of asthma health outcomes. *'Priority'*, *'beliefs'* and *'frustration'* were prominent emergent themes. Patients were concerned with issues they confront day-to-day, and did not *prioritise* longer-term health promotion. Health professionals face time constraints, limiting their ability to establish rapport, deal with multiple social and health problems, and provide asthma education. *Beliefs:* patients often accepted that their symptoms must be tolerated. Reliance on health professionals during acute exacerbations was their focus, rather than longer-term self-management and prevention strategies. Health professionals expressed *frustration* about lack of patient adherence to preventative self-management strategies whereas patients were *frustrated* with the inconvenience of asthma management regimens. The findings highlight the mismatch between the medical model of health education that places the individual's medical condition at the centre, and patients' realities set within social, economic and cultural contexts, which are often 'others-orientated'.

Keywords

Asthma, patient education, qualitative research

(NZFP 2008; 35: 257–262)

Introduction

Fifteen per cent of adult New Zealanders are affected by asthma and the incidence is rising.[1] Despite similar prevalence, there are disproportionately high mortality and morbidity rates from asthma in Maori compared with non-Maori,[2] reflecting a pattern of health inequalities for Maori that is apparent for many other medical conditions.[3] The overall cost of asthma to the New Zealand health care system is estimated to be between $375 and 800 million per annum of which 77% of the cost is attributed to asthma that is not well controlled.[1]

Asthma is often inadequately controlled and associated with preventable symptoms.[4] One reason for this is poor adherence to prescribed medication.[5] Asthma education is one strategy for improving adherence, as it can assist patients in understanding and managing their condition. Involving patients in treatment decisions is thought to encourage responsible self-management of their condition.[6] Effective communication and establishing a partnership be-

tween patients and health professionals has been found to contribute to the success of asthma education.[7] In addition, tailoring therapy to individuals and ensuring good patient–practitioner relationships can result in more effective health education.[8] More recent qualitative research, which focussed on only health professional views, suggests that while asthma guidelines help to provide the reasons why patients should be helped to manage their asthma, the guidelines are less clear in how to communicate these key messages.[9] It is therefore important to explore patients' as well as health professionals' perceptions of asthma education and management, as perceptions from both aspects of the therapeutic relationship may impact upon the success of education and use of preventative medication. In this preliminary summer studentship study we used one-to-one interviews, to allow in-depth exploration of the phenomena in question for a particular individual, with a view to undertaking a larger study exploring asthma management over the course of one year.

Tailoring therapy to individuals and ensuring good patient–practitioner relationships can result in more effective health education

Method

A layered qualitative analysis was employed that was consistent with the principles of Interpretative Phenomenological Analysis (IPA).[10]

Setting

Participants were recruited from a general practice serving an urban, lower socioeconomic area in Wellington. The practice had 6740 registered patients (23% European, 22% Pacific Island, 16% Maori, 15% Middle Eastern, 13% Asian, 10% African and 1% 'Other' ethnicities).

Participants

Five asthma patients and five health professionals who routinely saw asthma patients were recruited. Patients were purposefully recruited from the clinic and identified according to the following inclusion criteria: over 18 years of age, asthma diagnosis of greater than 12 months, current prescription of preventative asthma medication, and had previously received health education for asthma management. Exclusion criteria were inability to read and converse in English as interpreters were not funded for this study.

Of the five patient participants, three were Maori and two were New Zealand European. Four of the five had multiple co-morbidities as well as severe, inadequately controlled asthma (defined by recent acute hospitalisation or prednisone administration). The small number of patient participants was in part due to the study being conducted over the summer studentship period as well as the pilot nature of the work and the chosen methodology. The health professional participants consisted of three family physicians and two nurses working on the asthma management programme; all were New Zealand European.

Interview

The interview schedule included open-ended questions[10] about experiences of asthma, asthma medications, and asthma education. Several prompts were available to allow exploration of issues. Interviews were audio-taped, lasted between 40 and 60 minutes, and took place over a five-week period. Verbatim transcripts of interviews were prepared, using a transcript template.[10]

Data analysis

Various stages of verification (see below) ensured that the analytic and interpretative process was carried out in a robust manner.[11,10] The small number of participants is typical of this research methodology which argues that the research should be focused on providing an in-depth case-by-case analysis, affording time to conduct an iterative process of interpretation that was validated by research team members.

Interview transcripts were examined in stages. First, they were individually read and re-read to formulate ideas and insights. Each page was divided into three columns. The middle column contained the transcribed interview content (data) and the right column held thoughts, ideas and comments that arose during this preliminary analysis. The left column was used to detail keywords and themes that captured the essence of the script. This process was repeated with all transcripts, which enabled a master list of emerging key themes to be collated (VY). Key emerging themes were triangulated independently and in discussion with two other investigators (SD, CRE), resulting in a final set of themes. This procedure allowed the main themes to evolve as part of the re-iterative process.[12]

Results

Three of the primary themes that emerged were *'priorities'*, *'beliefs'* and *'feelings of frustration'* (Figure 1).

Priorities of patients and health professionals

Health professionals have been trained to believe that health education promotes long-term health benefits as one of the health professionals said:

'*..health education promotes good health which is ingrained into the health professional as they train.*' – HP* Angela

* 'HP' refers to a health professional's contribution.

Health professionals also believed that patients should be educated to self-manage chronic conditions like asthma.

'...what I would try to do is bring them round to a way of thinking that managing their asthma is their responsibility, not mine, and they're not doing it for me, they're doing it for themselves...' – HP Freda

The health professionals felt that informing patients about how to manage their condition was a duty that came with their role.

'I've got an obligation to let people know certain things...' – HP Gertrude

However, time pressures frequently meant that consultations were shorter than ideal. Lack of time for health professional–patient interactions may be a barrier to establishing rapport or having time to discuss individual concerns.

'...we're not sufficiently funded to do everything we would like to do for that population and so it's not uncommon for me to be working quite quickly um, in order to keep the waiting room under control.' – HP Boris

All the health professionals believed that health promotion education was worthwhile, but acknowledged that this belief was not always well-received by the patient. They felt this could be addressed by improving the health professional–patient relationship, which they thought was fundamental to the success of any patient education. However, many patients were not enthusiastic about managing their own asthma, often because they had other priorities in their lives, such as job, family, or church.

'I worry about people...my partner, my wife. Susan goes "don't worry about them, you worry about yourself, get yourself better first".' – Patient Jerome

Jacqui talked about how she neglected her health in favour of other things. She painted a picture of her life as being chaotic and stressful, and her co-morbid medical conditions being uncontrolled. She knew her life would be easier if her health problems were managed, yet she could not make time to deal with them:

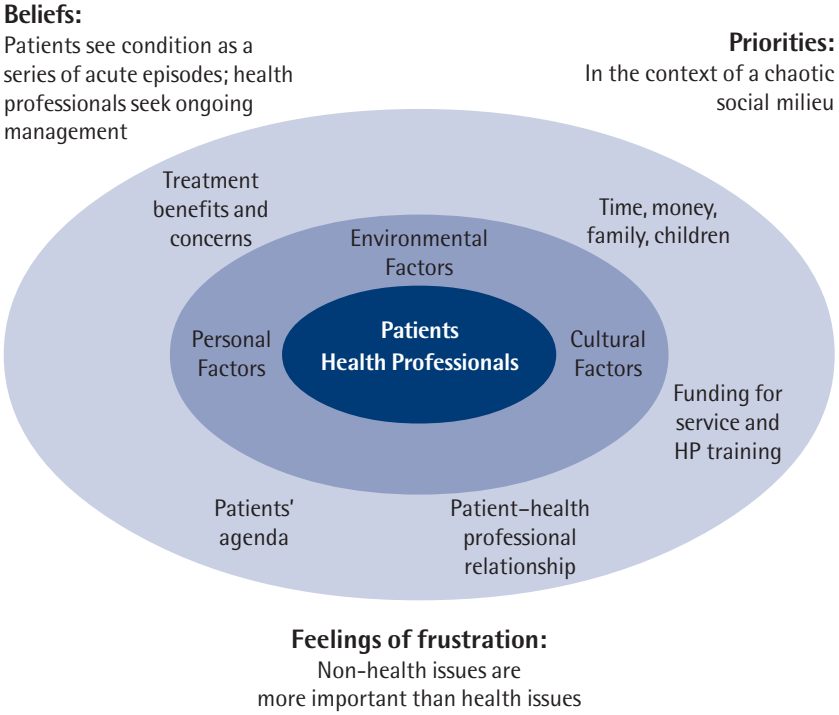
'I haven't been doing this, I haven't been doing that and I know I should be and you know, do my peak flows and all that. I'm busy, coming back to that bloody busy...I've got the rest of the whanau I've gotta deal with and my main concern'd be my grandchildren...then I can get on with what I need to do for myself.'

Patients' lack of priority for self-management of their asthma was recognised by health professionals:

'It's not a priority for them. It's only a priority when they're sick. Too many other things are a priority that they're not interested.' – HP Gertrude

'...it's very rarely high on their priority, yeah, that's right, they want the letter to Work and Income and you know, a letter to Housing, and you know, this is the reality of life, you know. Life is more important, then maybe family, and then maybe health...You might be dealing with domestic violence and someone's need for accommodation, and their poorly controlled diabetes too. Asthma would be actually off the agenda for that consultation. I mean, that's the reality of working with a high needs population.' – HP Katrina

Figure 1. Themes emerging from the layered analysis



Patient beliefs about asthma

Patients did not always share the same beliefs as health professionals about asthma management. None of the patients felt that they had control of their asthma or that they could effectively self-medicate to maintain control. While some patients stated that they knew what to do, there seemed little awareness of the concept of 'self-management'. Disease monitoring measures like peak flow were made primarily to inform health professionals.

'...if you can't get your peak flow up, you know there's something wrong. You do have to go and see a doctor, you may need something else for it...like if you are recording it when you go to the doctor or A&E, you can tell them what's been happening.' – Patient Lucy

Patient participants often described their asthma as being uncontrolled. However, they generally accepted and tolerated their asthma

symptoms even though they could be treated.

'I've always had asthma on a daily basis. I've even tried different medications and different, you know, spacers and stuff like that.' – Patient Lucy

Lucy was resigned to the belief that her asthma would not improve since she had tried many medications and had not seen any improvement. Her aim was to maintain the current severity of her asthma and avoid any further decline:

'I can't see it getting any better, not now. But if I can maintain my, my management plan...' – Patient Lucy

This acceptance of asthma symptoms by patients was recognised by health professionals. If uncontrolled asthma was common in the family then asthma was often not seen as a problem.

'...if there's a family history of asthma and they have also a background where their experience has been of people's asthma not being well controlled, it's almost the norm to be wheezy and the norm to cough.' – HP Katrina

Feelings of frustration

Frustration was a common theme expressed by both health professionals and patients, although for different reasons. The frustration of health professionals was often directed towards patients. One health professional described how she was aware of such feelings but knew she had to prevent them affecting her professional role:

'No matter how frustrated I get, no matter how much I know they could be doing better and so on and so on...I've got to deal with feelings about that so it's not too [frustrating].' – HP Gertrude

There was evidence to suggest that much of the patients' frustration was related to the inconvenience of the medication or their asthma management regimens.

'Because when I'm taking it I take one puff then I don't wait a couple of minutes, I just wait a few seconds and then have another puff...because it's usually, I'm usually taking it either in the middle of the night or at some ungodly hour of the morning and I just really can't be bothered staying awake, you know, waiting around. Or, it's in the middle of doing something I just need to keep doing.' – Patient Lucy

This, and the following excerpt, illustrate that knowledge of the medication regimen does not automatically translate into performing the appropriate behaviour; another source of frustration for the health professionals as well as the patients – who do not feel they need to be told any more what they should be doing:

'I know everything I'm supposed to be doing and sometimes I'm not doing it but I still know what I should be doing, what I could be doing and what I should be doing...there is times when I sort of get lazy. Yeah, I don't know, I just get lazy, get out of habit and then try and pick it up again...Maybe just ah, um, oh usually it's just like I said before, I haven't picked up a prescription or something. Yeah, and then like two days later I just keep forgetting and I get used to not living with it so...until I get round to getting it...I can still survive without Flixotide, but the Ventolin, nah, I need it.' – Patient Tom

The lack of coherence in priorities appears to stem from the prevalence of the 'medical model' of education, which leads to a dissonance between health professionals' feelings of responsibility to deliver health education and the complex reality of patients' lives

Additionally, patients commonly expressed frustration regarding asthma itself as well as the treatments, and how asthma disrupted their lifestyle. One participant expressed how it interfered with her quality of life. She had been restricted by her asthma when she was younger and very little had changed since then:

'There are times that I resented having asthma because I missed out on things, even as an adult I couldn't go, do things because of my asthma. You know, it was just so inconvenient. It'd come when I least had wanted it.' – Patient Jacqui

Discussion

The main finding emerging from this study is the lack of coherence in priorities and beliefs between health professionals and participants. The health professionals often seemed aware of this mismatch. Health professionals also demonstrated that they have a good insight and understanding of the issues affecting their patients but were frustrated at their inability to address many of these issues.

The lack of coherence in priorities appears to stem from the prevalence of the 'medical model' of education, which leads to a dissonance between health professionals' feelings of responsibility to deliver health education and the complex reality of patients' lives. Although this might be a simplistic explanation it is consistent with the findings of Jones and colleagues who explored views of using guided self-management plans for asthma.[13] However, in the current study, health professionals were aware that their model of education was often unsuccessful. They acknowledged the patients' competing priorities and that these may be obstacles to the delivery of effective asthma education. Similarly, the disconnect between patient and health professional behaviour may stem directly from factors in the patients' lives and that a less than perfect management of asthma was tolerable to patients.

Lack of coherence was also evident in the beliefs about asthma. While the health professionals treated asthma

as a chronic condition that required management on a daily basis, the patients often approached it as a recurring acute, on-off, condition that required doctors' attention only when symptoms became excessive; this acute episodic belief has been associated with poor self-management in a similar urban population.[14] On the other hand there was coherence emerging in the feelings of frustration expressed. These feelings also seem to have been related to the mismatch of the model of health education used versus the patients' reality. While frustration was felt by the patients due to their lack of control over their asthma, they possibly also did not regard it as such a big health issue as their health professionals. In contrast health professionals were frustrated due to the lack of success of their messages within the education and prevention programmes.

The barriers to asthma education and prevention are often socioeconomic and cultural, which means they are not easily overcome.[15] Patients often put other priorities ahead of taking care of their health. In this study, patients were mainly 'others' orientated. That is, they put others before themselves, and tended to prioritise the family (whanau), the church, or economic factors, over themselves. This needs to be recognised, as the medical system usually places individual patients or their condition at the centre of action. Competing forces in patients' lives are not necessarily acknowledged in the medical model. Lifestyle, socioeconomic, cultural and educational factors are all known to influence asthma[1] and were clearly expressed by both health professional and patient participants in this study as affecting patients' ability to self-manage.

Participants were typical of patients with multiple health problems and complex social situations from a lower socioeconomic area. Such patients have been reported to be the most likely to be non-adherent for many reasons

Previous research on the perceptions of health professionals and patients with asthma is limited. Sweeney and colleagues conducted a qualitative study in which eight focus groups (four with health professionals, four with asthma patients) also revealed differing concepts about the disease.[16] Views about asthma self-management plans were explored in other qualitative studies,[13,9] which found that guided self-management plans were not popular with either health professionals or patients, but for differing reasons. The current study provides some insight into why such self-management plans are often not successful, as acute problems are prioritised over prevention (both social and medical) and such plans are individual-focused and assume patients see their asthma as an ongoing health condition that they are responsible to manage, instead of an episodic condition outside of their control that should be managed by health professionals when it arises.[14]

Lifestyle, socioeconomic, cultural and educational factors are all known to influence asthma and were clearly expressed by both health professional and patient participants in this study as affecting patients' ability to self-manage

Several studies have considered patients' perceptions in isolation. One study conducted interviews with asthma patients to explore their attitudes to medication.[17] The authors classified participants into three groups: 'deniers', 'acceptors' and 'pragmatists'. The current study has also identified the wider family, social, economic and cultural context which plays an important role in priorities, beliefs and adherence to asthma education and management.

This exploratory study has also found that knowledge does not necessarily translate into action. One patient talked about the inconvenience of her medication regimen, so that although she was aware of the prescribed treatment, she chose to ignore it. This is known as intentional non-adherence[18] and reflects the complexity of the situation facing our participants. In contrast 'unintentional non-adherence' – for example when a patient fails to recall the complexities of the treatment – can be remedied by providing more information or memory aids. Our findings are therefore consistent with the behaviour change model explaining the interaction between personal and environmental factors with behaviour.[19] The patient does not perceive a significant benefit (personal factor) in taking the medication as prescribed. Thus, it is believed that the benefits gained by taking the medication and promoting health are outweighed by concerns regarding side effects,[20] the inconvenience of implementing these behaviours or by other competing priorities. Other personal factors known to affect behaviour, such as motivation, confidence and skills/strategies, were not major themes found in this study.

Strengths and limitations

This qualitative study was conducted with a small number of participants (10), which is consistent with the idiographic, or case by case, approach taken, and allowed in-depth analysis of each participant's story. However, in the context of a qualitative research paradigm the conclu-

sions from the current study cannot be generalised to different populations. Nevertheless, participants were typical of patients with multiple health problems and complex social situations from a lower socioeconomic area. Such patients have been reported to be the most likely to be non-adherent for many reasons.[15] Therefore, targeting this group could result in the most significant improvement in health outcomes; results from this study have been incorporated into the design of a year long exploration of seasonal variation in childhood asthma and its management in Maori families.

Conclusion

The results highlight the complexity of patient–health professional relationships, particularly the disconnect between the model of health education that places the individual's asthma and their ongoing management at the centre, and patients' beliefs of an on-off disease that is set within the complex reality of their social, economic and cultural context and which is often 'others-orientated'. It is important that further enquiry acknowledges and involves the wider group of people that form part of the patient's life, and includes the health issues of both the patient and the wider family. This study is currently under way. Educational programmes to encourage the self-management of asthma may be more successful if we can find ways to develop interventions that will enable the prioritisation of health prevention in an often chaotic social milieu.

Acknowledgements

We would like to thank the practice staff and patients who made this study possible and the Asthma and Respiratory Foundation of New Zealand (Inc.) for supporting a summer studentship for Vanessa Young.

Ethical approval

The Wellington Regional Ethics Committee approved the study prior to recruitment. Researchers consulted with clinic staff, Maori Roopu (Maori advisory committee of the practice) and the University of Otago Maori research committee during study design. Participants gave informed consent prior to being interviewed. Pseudonyms have been used for all participants.

Competing interests

None declared.

References

1. New Zealand Guidelines Group (NZGG). Best practice evidence-based guideline: The diagnosis and treatment of adult asthma. Wellington, New Zealand: NZGG; 2002.
2. Ellison-Loschmann L, Pearce N. He Mate Huango: an update on Maori asthma. Pacific Health Dialog 2000; 7: 82-93.
3. Harris R, Tobias M, Jeffreys M, Waldegrave K, et al. Effects of self-reported racial discrimination and deprivation on Maori health and inequalities in New Zealand: cross-sectional study. Lancet 2006; 367: 2005-09.
4. Rabe KF, Adachi M, Lai CK, Soriano JB, et al. Worldwide severity and control of asthma in children and adults: the global asthma insights and reality surveys. J Allergy Clin Immunol 2004; 114: 40-7.
5. Williams LK, Pladevall M, Xi H, Peterson EL, et al. Relationship between adherence to inhaled corticosteroids and poor outcomes among adults with asthma. J Allergy Clin Immunol 2004; 114: 1288-93.
6. Chapman KR, Walker L, Cluley S, Fabbri L. Improving patient compliance with asthma therapy. Respir Med 2000; 94: 2–9.
7. Partridge MR. Delivering optimal care to the person with asthma: what are the key components and what do we mean by patient education? Eur Respir J 1995; 8: 298–305.
8. Cochrane GM, Horne R, Chanez P. Compliance in Asthma. Respir Med 1999; 93: 763-769.
9. Moffat M, Cleland J, van der Molen T, Price D. Poor communication may impair optimal asthma care: a qualitative study. Fam Pract 2007; 24(1):65-70. Epub 2006 Dec 7.
10. Smith JA, Osborn M. Interpretative phenomenological analysis. In: Smith JA, editor. Qualitative psychology: A practical guide to research methods. London: Sage Publications; 2003. Chapter 4.
11. Yardley L. Dilemmas in qualitative health research. Psychol Health 2000; 15: 215-228.
12. Dean SG, Smith JA, Payne S. Low back pain: exploring the meaning of exercise management through Interpretative Phenomenological Analysis (IPA). In: Finlay L, Ballinger C, editors. Qualitative research for allied health professionals: Challenging choices. Chichester: John Wiley and Sons Ltd; 2006. Chapter 10.
13. Jones A, Pill R, Adams S. Qualitative study of views of health professionals and patients on guided self management plans for asthma. BMJ 2000; 321: 1507-1510.
14. Halm EA, Mora P, Leventhal H. No symptoms, no asthma. The acute episodic disease belief is associated with poor self-management among inner city adults with persistent asthma. Chest 2006; 129(3): 573-580.
15. George M, Freedman TG, Norfleet AL, Feldman HI, Apter AJ. Qualitative research-enhanced understanding of patients' beliefs: Results of focus groups with low-income, urban, African American adults with asthma. J Allergy Clin Immunol 2003; 111: 967-973.
16. Sweeney KG, Edwards K, Stead J, Halpin D. A comparison of professionals' and patients' understanding of asthma: Evidence of emerging dualities? J Med Ethics 2001; 27: 20-26.
17. Adams S, Pill R, Jones A. Medication, chronic illness and identity: the perspective of people with asthma. Soc Sci Med 1997; 45: 189-201.
18. Horne R. Representations of medication and treatment: Advances in theory and measurement. In Petrie KJ, Weinman JA, editors. Perceptions of health and illness. Amsterdam: Harwood Academic Press; 1997. Chapter 1.
19. Maibach EW, Cotton D. Moving people to behaviour change: a staged social cognitive approach to message design. In: Maibach E, Parrott RL, editors. Designing health messages: Approaches from communication theory and public health practice. California: Sage Publications; 1995. In: Sport and Recreation New Zealand. Obstacles to action. A study of New Zealanders' physical activity and nutrition. Wellington: SPARC; 2003.
20. Horne R, Weinman J. Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventor meidcation. Psychol Health 2002; 17(1): 17-32.