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Identifying patients with asthma whose beliefs and attitudes may place them at risk: the development and initial validation of the Asthma Navigator

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Identifying patients with Asthma whose beliefs and attitudes may place them 'at risk': The development and initial validation of the *Asthma Navigator*

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Asthma prevalence appears to be increasing in Australia and elsewhere and any methods that can improve the self-management of asthma can in turn help improve the quality of living experienced by these individuals and at the same time reduce health costs to the nation. Attempts that have aimed at making a difference in asthma management have focussed on educational programs (preventive therapy) and the nature of the physician-patient relationship. However, most tools (questionnaires) available for the measurement of beliefs, feelings and attitudes of those with asthma appear to be generalised research instruments. They have not been designed to assist the physician directly in the day-to-day consultations or to help in providing practical guidance on asthma treatment and behaviour change that will make a difference. This article describes the development of the *Asthma Navigator*, a questionnaire designed to address this situation, to be used in consultation and discussion between the physician and the patient and to help improve the outcomes possible in asthma treatment and management. Particular reference to the psychometric properties of the questionnaire is made.


Introduction

There is a continuing severity of asthma attacks in Australia and elsewhere and a continuing relatively low degree of adherence to treatment (see, for example, Abramson, Kutin, Rosier, Bowes, 1995; Campbell, Latimer & Luke, 1996; Paterson, Peat, Mellis & Woolcock, 1997; Wakefield, Staugus & Ruffin, 1997; and Watts, McLennan, Bassham & El-Saadi, 1997). Methods that can contribute significantly to increased treatment adherence and to improved health outcomes in the management of asthma are welcomed. This article reviews briefly approaches that have been adopted in targeting improved attitudinal and behavioural outcomes in asthma management. It then discusses the recent development of the *Asthma Navigator*, a tool or questionnaire for physician use aimed at assisting in

the physician-patient relationship and improving outcomes in treatment compliance and asthma management.

In the past decade, considerable attention has been given to educational programs and knowledge presentation as ways of improving asthma treatment compliance. Multifaceted educational activities targeting health care professionals, people with asthma, and the general public, have significantly improved knowledge about preventive asthma therapy in Australia (e.g.; Comino, Bauman, Mitchell, Ruffin, Antic, Zimmerman & Gutch, 1997). These initiatives have also been associated with significant reported improvements in airway function measurement practices, the use of preventive therapy and the use of written action plans in primary care (Tse, Bridges-Webb & Bauman, 1993). However, health surveys have suggested that self-reported asthma prevalence was increasing in Australia during the same period and, further, that a gap remains between current asthma management practice and that recommended by the Australian National Asthma Campaign (e.g.; Adams, Ruffin, Wakefield, Campbell, & Smith, 1997).

However, one international meta-analysis and review of 11 randomised trials of self-management teaching programs in children with asthma concluded that educational programs improve knowledge but *do not reduce morbidity*, and that programs should focus on more immediate outcomes such as behaviour change rather than education (Bernard-Bonnin, Stachenko, Bonin, Charette & Rousseau, 1997). In line with these findings a New Zealand-based investigation of clinical and psychosocial factors associated with knowledge and behaviour found marked differences between patients' self-management knowledge and their actual behaviour, particularly in terms of potentially life-saving actions in acute asthma exacerbations. This study suggested that improved understanding of the discrepancies between knowledge and behaviour may lead to more effective asthma educational interventions (Kolbe, Vamos, Fergusson, Elkind & Garrett, 1996).



The role of the physician in using and mediating such understanding may be crucial. The nature of the physician-patient relationships in successful management of asthma has been investigated in several studies (for example: Kolbe, Vamos, Fergusson, Elkind & Garrett, 1996; Adams, Pill & Jones, 1997; Clark, Gotsch & Rosenstock, 1993; Snadden & Brown, 1992). Snadden and Brown (1992) used interpretive research methods to characterise the dynamics of the asthma experience and noted the importance of what they called a 'mentoring' relationship. Kolbe and colleagues found that aspects of the physician-patient relationship – including confidence in the doctor's management, feeling understood by the doctor, and level of information offered by the physician – were associated with self-management knowledge and behaviour in acute severe asthma (Kolbe, Vamos, Fergusson, Elkind & Garrett, 1996). However, none of these studies has made clear recommendations to family physicians about the specifics of a successful clinical approach or provided simple clinical tools and infrastructure to facilitate this process.

We set out to devise a psychometric instrument – the *Asthma Navigator* – capable of assisting family physicians applying usual clinical skills, and within the setting of usual Australian general practice, to (i) identify internal arguments used by patients whose beliefs and attitudes regarding asthma might be putting their health at risk; (ii) challenge those arguments; and (iii) introduce other arguments that might support behaviour more likely to yield optimal health outcomes.

Examination of the literature suggested that there were no extant questionnaires dealing with asthma and its management that covered what we saw as being needed. Several instruments designed to assess the contribution of beliefs, feelings and attitudes of those with asthma towards their condition and its impact on treatment were identified and these have been described in journal articles elsewhere (e.g., Creer, Wigal, Tobin, Kotses, Snyder & Winder, 1989; Katz, Yelin, Smith & Blanc, 1997; Kolbe, Vamos, James, Elkind & Garrett, 1996; Letrait, Lurie, Bean, et al, 1996; Richards, Dolce, Windsor, Bailey, Brooks & Soong, 1989; and Wigal, Stout, Brandon, Winder, McConaughy, Creer & Kotses, 1993). However, most of these instruments were designed for the purposes of research into psychological and behavioural aspects of asthma. Few have looked in depth at the importance of the doctor-patient relationship. None appears to have been designed for use by primary care physicians in the course of day-to-day consultations with people with asthma, or to provide practical guidance in relation to asthma treatment and behaviourally-focused interventions with the aim of enhancing adherence and minimising risk. We proceeded with the development of *The Asthma Navigator*.

The initial approach was a qualitative study of the beliefs, attitudes and feelings of people with asthma. This study was carried out preparatory to possible questionnaire development. As part of the study 70 adults with asthma were interviewed

extensively (Harris & Shearer, in press). Their responses were categorised and classified in order to identify elements of Toulmin-type argument structures (Toulmin, 1958) and of the attitudes and beliefs supporting the behaviour of adults with asthma (Harris & Shearer, 2001). These attitudes and beliefs might explain why 'knowledge' does not necessarily change behaviour. Script and theme categorisations of the statements made during these interviews suggested some 14 major dimensions or themes common to many of the interviewees (discussed later as part of the questionnaire development). However, more significantly, four differing sub-groups or streams of people (adults) with asthma could be identified. These "streams" of people with asthma were characterised by differing beliefs and attitudes over certain key domains: the individual's response to asthma, beliefs about medication and specific medication types, beliefs about the role of doctors, and beliefs about the value of a relationship with a doctor.

This information on the identified dimensions and streams or types of people with asthma in terms of their beliefs, attitudes and feelings, formed the basis for the next more quantitative stages in the development of the *Asthma Navigator*. First, more information on the four streams:

Of the four streams, the stream 1 group was seen to comprise individuals who experience infrequent symptoms of asthma, doubt that their symptoms are really asthma, use inhaled bronchodilators irregularly, have only limited awareness of asthma or its risks and rarely visit health professionals; these individuals were characterised as **anonymous** (to the health system). Since our research group was concerned more with those who make contact with health care professionals, we were more interested in those classifiable into the remaining three streams.

Stream 2 comprised individuals who feel dependent on bronchodilators, have frequent symptoms, disrupted lifestyles and repeated acute asthma exacerbations. Their attitudes towards asthma and medication range from denial to passive acceptance, and they have limited knowledge about asthma and the roles of medications. These were characterised as **isolated**.

Individuals in Stream 3 are confident they are maintaining good asthma control, usually in comparison to a less stable past history. They tend to attribute improved control to a successful working relationship with one primary care physician. While they comply with an agreed plan to control their asthma, however they normally continue to use inhaled bronchodilators frequently and to suffer lifestyle constraints because of their asthma. This stream was characterised as **suboptimal**.

Those in Stream 4 are also confident of their asthma control, but expect to lead unconstrained, symptom-free lifestyles. They accept constraints only after exhausting management options and remain alert to new options. They also attribute their control of asthma to a working relationship with one physician and comply fully with an agreed

management plan, seeking appropriate review. This stream was characterised as representing an optimal approach.

People in streams 3 and 4 reported that the physician responsible for assisting their change in behaviour had involved them in a 'partnership' that pursued a process of inquiry, information, task identification, review, and feedback. This is consistent with findings from research on physician-patient relationships already described above and in other papers (e.g., D'Epiro, 1999; Shelton, 1995). Moreover, the physician did not appear to require extraordinary clinical skills or training, new systems or external inputs in order to facilitate this process. It was thought by the initial team of researchers (Harris, Shearer and Smith, personal notes) that a questionnaire could assist in this relationship; and could be a strong factor in helping people move from stream 2 (most at risk) or stream 3 to the optimal stream 4. At this point the first of the authors of the current article (Hicks) was asked to join the team and assist in the item writing and questionnaire development and in research design and statistical analysis related to the questionnaire and the outcomes desired. This paper reports on that development.

Design and Methodology

Several phases were involved in the questionnaire design, development and analysis. In the first phase (qualitative interview research and planning), the four main streams were identified, as already described, as were fourteen dimensions. In addition a literature review suggested that a further six dimensions might also underlie the beliefs, attitudes and feelings of people with asthma. It was thought that a final questionnaire of about 100 items would be sufficient for reliability and validation purposes and would be acceptable to the physicians and patients. In the next phase and to ensure that the items were the best possible rather more than the 100 items needed to be written and then subjected to intensive analysis. In this second phase therefore some 250 items were written that related to each of the streams and dimensions being researched (only the best of the items were to be used in the final questionnaire including those that were content-valid and also statistically valid- as described later; and the additional number of items enabled choice).

In the third phase these 250 items were reviewed by 14 "subject matter experts" (panel of experts in health care) – and deletions, changes to wording and content made as required. In addition a small group of 13 people with physician assigned asthmatic categorisation (into one of the streams) was given the research questionnaire and the responses again examined for general confirmation of the item-category and item-stream relationships. Thus, the initial relevance of the items and dimensions was to be determined by consideration of the responses of the expert review panel (for content analysis) and by consideration of the responses from the small pilot

group of stream-assigned asthmatics.

The expert review panel comprised 14 Australian general practitioners (family physicians) and other asthma care professionals. These respondents were asked to examine each of the 250 items in turn and indicate whether the item contributed to one, two, three or four or more of the 20 dimensions of the study plus the four streams. The panel members simply "ticked" the categories that they saw as related to the item. This lengthy and arduous task provided an extensive grid for content analysis in terms of agreement and consistency across the dimensions (Hicks, 1997, 1998). The results are described in the Results Section.

Items accepted for inclusion in a dimension or stream in the final questionnaire were those that received most agreement with respect to the dimension. In all cases the items chosen were those where at least 60% of the expert panel were in agreement concerning categorisation into any one dimension. This level of agreement helped to ensure reasonable *content validity* for each of the dimensions/categories, before the next qualitative and statistical analyses were carried out.

The 250-item research questionnaire was also administered to 13 asthmatics who were identified by GPs as falling into one of streams 2, 3 or 4 on their medical assessment. This provided a group of asthmatics with known categorisation as a further aid in assessing the items, and their responses were used as back-up support for inclusion or rejection of items where marginal agreement on the item categorisation existed from the expert panel. The small pilot group of "stream-allocated" asthmatics was also used in similar fashion to the "subject experts" to provide further indication to support rejection or selection of items.

Expert panel members were used in an ongoing participative and iterative manner to help determine the final decisions about both *item* and *dimension* inclusion (that is, the development of the questionnaire proceeded along expert judgment lines with the subject matter experts being involved continually). This analysis resulted in a 96-item questionnaire in which all items were considered to be strong representatives of their dimensions (initially there were 97 items, but one item was subsequently deleted when it failed selection criteria).

The fourth phase was the administration of the questionnaire to a sample of respondents with asthma. In this fourth phase (quantitative research stage) the selected items were incorporated into a final questionnaire that was completed by 360 respondents. Statistical analyses were applied to determine whether the reduced number of chosen items and the ten dimensions for the final questionnaire met sound internal and external reliability standards (see results presented in Tables 1 and 2). The questionnaire scores were also examined statistically in terms of factor analysis (varimax) to determine the underlying structure of the questionnaire. The results section expands these comments (see comments and Table 2) and also indicates the subsequent development of the factor-

dimension categories (see Table 3) that play a significant part in the practical use of the questionnaire.

Further comments on method and process

The 97-item questionnaire was administered by personal interview or by telephone interview to 360 people with asthma. These were selected at random until about 120 respondents from each of three Australian cities were obtained. A survey company was used for the sampling and interview-questionnaire completion strategy. Trained interviewers administered the questionnaires, half in written form, half orally over the phone. Subsequent analyses of the means and variances for the final dimensions showed no significant differences between the two data collection methods (Hicks, 1998).

As a further example of the iterative process used as part of the methodology in the questionnaire development and interpretation, once the factor-structure of the questionnaire was identified, the three factor-dimensions were also incorporated into the individual reports for the Asthma Navigator giving additional data beyond the results on the confirmed ten dimensions (Hicks, 1998). Further, as a very strong relationship became apparent between the four stream dimensions and a *composite* of two of the underlying factor dimensions (now called the *FDT* or Factor Dimension Total) the single FDT score replaced the four separate stream allocation or stream dimension scores. By using the FDT score it is possible to allocate individuals to one of the four streams (anonymous, isolated- at risk, sub-optimal, optimal). The separate stream data (four separate stream dimensions independent of the FDT) is not needed in the allocation of individual asthmatics to relevant streams as the FDT now does this: but this data on the four separate stream scores and the FDT-allocated scores provided further evidence on the internal validity of the questionnaire.

Results

As indicated above, the initial body of 250 questions was refined by analysis of the responses from the subject matter experts and the group of individuals with asthma to just ten dimensions and 96 questions. Subsequent statistical analysis (comparisons of the item with the dimension-total scores) in the final questionnaire led to confirmation of the majority of these items as statistically relevant (a positive correlation with the total dimension score of 0.30 or better was set as the "rule-of-thumb" approach for selection). Only those items which passed this standard were retained in the scoring procedures for the dimension reports. Five items below 0.30 but in the .20's were retained in the questionnaire for future research but do not contribute to dimension scores in the current use of the questionnaire.

Following the qualitative and quantitative methods outlined above, the 96 items covering the ten dimensions and the four streams were confirmed as highly relevant and likely to be most useful in the Asthma Navigator.

The internal reliability and validity results are presented in the next section. For case of reference the ten dimensions are listed in Table 1, and their reliability coefficients are given in Table 2. It should be noted that the most representative score concerning the overall reliability of the Asthma Navigator is the Alpha Coefficient of 0.91 obtained for the Factor Dimension Total. Table 3 shows the *inter-correlations* among the ten dimensions and the FDT score. Other data, including test-retest data are given in subsequent sections.

Table 1

The 10 dimensions in the Asthma Navigator

Dimension	Continuum describing essence of dimension
1. Feelings	Anger/Imposition/ Resignation → Acceptance/ Control
2. Acknowledgment	Denial → Acceptance
3. Risk consciousness	Low → High
4. Risk management	Outside personal control → Within control
5. Knowledge level	Not informed → Informed
6. Information searching	Passive → Active
7. Doctor - patient relationship	Passive Prescriber → Partnership
8. Attitude to bronchodilator 1	Relieves asthma → Relieves symptoms
9. Attitude to bronchodilator 2	Dependence → Management tool
10. Attitude to use of preventer medicines	Indistinct → Distinct from bronchodilators.

Table 2

Internal reliability figures (Cronbach Alpha coefficients) for the ten dimensions and the factor-dimensions of the Asthma Navigator (N= 360; adapted from Table 2 of Hicks, 1997)

DIMENSIONS	ALPHA:
Feelings about having asthma (Dim 1)	.78
Acknowledgement (Dim 2)	.64
Risk consciousness (Dim 3)	.62
Risk management (Dim 4)	.71
Knowledge level (Dim 5)	.75
Information searching (Dim 6)	.67
Doctor - patient relationship (Dim 7)	.67
Attitude to bronchodilator 1 (Dim 8)	.71
Attitude to bronchodilator 2 (Dim 9)	.77
Attitude to use of preventer (Dim 10)	.80

Factor - Dimensions Alpha

FACTOR Dimension Total (FDT): overall asthma beliefs (dims 2-10)91
FACTOR DIM 1: Active awareness & action (dims 2, 3, 4, 6, 7)84
FACTOR DIM 2: Medical knowledge/beliefs (dims 5, 8, 9, 10)94
FACTOR DIM 3: Positive feelings & patient-doctor relations (dims 2, 7)78

Table 3

Correlation matrix relating the ten dimensions, and the FDT (based on N= 360).

(Coefficients over 0.25 are significant beyond the .01 level). (Adapted from Hicks, 1998)

	Dimesions #									
	1	2	3	4	5	6	7	8	9	10
1. Feelings	1.00									
2. Acknowledge	0.05	1.00								
3. Risk conscious			0.03	0.75	1.00					
4. Risk management	0.16	0.66	0.76	1.00						
5. Knowledge	0.07	0.54	0.60	0.74	1.00					
6. Searching	-0.05	0.69	0.64	0.55	0.63	1.00				
7. Doctor - patient	0.32	0.35	0.33	0.33	0.27	0.20	1.00			
8. Attitude med-1	0.06	0.31	0.43	0.56	0.73	0.49	0.16	1.00		
9. Attitude med-2	0.03	0.30	0.48	0.66	0.72	0.44	0.16	0.82	1.00	
10. Attitude med-3	0.13	0.42	0.56	0.73	0.86	0.50	0.29	0.77	0.84	1.00
FDT: Total Score	0.12	0.73	0.81	0.87	0.88	0.75	0.45	0.76	0.79	0.87

See Table 1 for extended titles of the dimensions

Internal Reliability Figures

As shown in Table 2, *Cronbach Alpha* reliability coefficients were calculated for the FDT dimension, the three factor-dimensions and the ten individual dimensions. The FDT figure is most representative of

the reliability of the whole questionnaire ($r = 0.91$) as its items include the majority (80) of those in the questionnaire. Also the FDT is a highly significant part of the questionnaire since it is used to categorise patients into category streams.


The reliability coefficients for the three factor dimensions (active awareness, medical knowledge, feelings re asthma and doctor-patient relationship) are also given ($r = 0.78$ to 0.94). The coefficients for the ten dimensions separately are given; these average 0.73 and range from 0.62 to 0.80 . The difference in the level of the coefficients as compared with the factor-dimension scores is consistent with the smaller numbers of items per specific dimension category. There are from 8 to 15 items per dimension among the ten dimensions, 26 in Factor Dimension 3 and from 43 to 80 for Factor Dimensions 1, 2 and the FDT Total.

Table 3 shows the inter-correlations among the ten dimensions and the FDT dimension. Dimension 7 on the doctor-patient relationship forms together with Dimension 1 the third factor identified in the Asthma Navigator: the dimension relates most to patient feelings, acknowledgement, and risk knowledge and management. Relatively strong relationships ($r = 0.27, 0.29$) are also identified with knowledge level and attitude towards the use of preventers. Overall the strong relationship of the nine dimensions to the Total score is apparent.

As indicated above varimax factor analysis revealed three major related factors underlying the *Asthma Navigator*: a factor-dimension dealing with asthma awareness, acceptance and management (FD1); a factor-dimension dealing with beliefs and knowledge about medication (FD2); and a factor-dimension dealing with patient feelings and perceptions of the doctor-patient relationship (FD3). The analysis revealed inter-correlations of these factors as follows: FD1:FD2, $r = 0.64$; FD1:FD3, $r = 0.42$; and FD2:FD3, $r = 0.20$.

External Test-Retest Results

The *Asthma Navigator* was administered on three occasions over four months, nine months and twelve months in separate studies as part of a program to assess its test-retest reliability over shorter and longer periods. For the first study over four months seventeen individuals with asthma completed two administrations of the questionnaire. A detailed analysis of the scores was carried out comparing each individual's sets of responses (paired responses) over all 96 items of the questionnaire, yielding a Pearson-Product Moment correlation coefficient (PPM r). This whole-test comparison yielded a mean coefficient of 0.75 , and a range of coefficients from 0.61 to 0.92 for the 17 individuals. Analysis of the overall profile responses of the individuals, on their profiles of scores over all dimensions, yielded a mean coefficient for these 17 profile comparisons of 0.76 and a median coefficient of 0.82 .



In a second study, the figures obtained for a nine-month period in a larger sample showed PPM $r = 0.79$, for $n = 132$; and in the third study over a slightly longer period of about 12 months showed PPM $r = 0.72$, for a sample of $n = 184$.

Discussion

The Asthma Navigator, which is designed to be used in the setting of routine family practice appears to provide a reliable means of identifying clinically-relevant behavioural issues. As indicated above and in the Technical Manual on the Asthma Navigator (Hicks, 1998) the streams and dimensions intrinsic to its structure hold up well to testing, reliability analysis and test/re-test checking. The obtained internal reliability (*Cronbach Alpha*) coefficients and the test-retest coefficients indicated above are consistent with figures obtained for well-established questionnaires of personal characteristics (cf; Groth-Marnat, 1990).

The initial identification of four streams based on the focus interviews and qualitative analyses also held up during the expert panel stage and in the statistical analyses. There was no item or dimension which panel members felt called for an additional stream beyond those outlined. Items and dimensions were generally categorised into one or more of the four streams with relatively little difficulty. The four-stream model also held up in the statistical analyses, and was found to be related strongly to a composite factor-dimension that combined the major elements of items and dimensions developed for the questionnaire. This Factor Dimension T score (FDT) score is thus now used to identify stream allocation.

Allocation of the respondent into one of four streams is an essential outcome of the questionnaire, allowing doctors and patients a first overall appreciation of the stream into which the patient falls. However, more detailed identification of levels on each of the ten dimensions allows the clinician to focus attention on these specific aspects where they may be important in the internal argument structures or beliefs of people with asthma. The results help the doctor to focus on belief structures that should be challenged and may yield opportunities to introduce the patient to belief patterns and arguments that better support behaviour change and optimal health outcomes.

The initial qualitative and literature research suggested that issues relating to depression, self-esteem or dependence-independence, while important for some individuals, are not concerns common to the majority of people with asthma. The Asthma Navigator does capture some aspects of affect and self-esteem: for example, feelings associated with depression are incorporated in Dimension 1 and aspects relating to autonomy and locus of control are

involved in Dimension 4. However, in general the emphasis in the Asthma Navigator is on the streaming and the levels attained in each of the Factor and the dimension categories identified.

Conclusions

The Asthma Navigator appears to be a robust, reliable and content-valid source of information on persistent beliefs, attitudes and behaviours that may be relevant to doctor-patient partnering relationships and ultimately to health outcomes for people with asthma.

We are currently investigating the use of the Asthma Navigator in the setting of Australian general medical practice. We see the Asthma Navigator as a tool for informing primary care physicians about attitudes held by their patients with asthma and the behavioural changes that they may be able to initiate in people whose beliefs and attitudes about asthma may place them at risk. The Asthma Navigator does not replace but complements clinician/patient contact and history taking, providing reliable and valid information on patient attitudes that may affect treatment compliance. Preliminary results from our investigations have shown strong behavioural changes in patients where the Asthma Navigator is being used as a tool to aid in the consultations with patients in partnership programs (reported as work in progress, e.g., Harris & Hicks, 2000, Hicks & Harris, 2000). These outcome validation studies and results will be reported fully in due course.

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