Is avoidance of chronic, moderate-severe child asthma a potentially non-adaptive response by patients and informal caregivers?

A view of medical practitioners

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ABSTRACT

Avoidance is typically conceptualised as an expression of coping with either distress (state avoidance) or goals set by an optimistic life attitude (trait avoidance). What medical practitioners believe about avoidance underpins their clinical behaviour. This paper aims to consider whether community-based practitioners of medical care conceptualise avoidance of chronic, moderate-severe child asthma as coping. The research was qualitative, involving personal interviews with a maximum variation sample of 10 general practitioners (GPs) and two community-based paediatricians in the Auckland region. Analysis of transcribed interviews was undertaken independently by two researchers through a general inductive approach. The sample suggested that avoidance by asthmatic children, their informal caregivers, or both can be a non-adaptive response to asthma in the absence of a perceived need to cope. Such avoidance can involve normalisation and minimisation of symptoms.

Appropriate GP management of avoidance depends on identifying the nature and effectiveness of avoidance in the context of knowing each child and its caregivers.

Key words

Avoidance, coping, stress, GP

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Introduction

Commonly conceptualised as a mechanism for coping,[1] avoidance refers to cognitive distraction and behavioural avoidance.[2] Cognitive distraction includes rationalisation or bolstering (reappraising an illness to diminish any threat). Behavioural avoidance includes procrastination (delaying a decision to seek health care) and shifting to someone else the responsibility for making and acting on a decision whether to seek health care.[3]

Avoidance can be used to cope with distress (state avoidance) or with goals associated with positive stress (trait avoidance),[4] as reflected in an optimistic life attitude. The latter form of coping has been described as 'proactive coping.'[5] However, in response to child asthma, does avoidance necessarily signify a form of coping by patients (asthmatic children) or their (informal) caregivers? If not, what are the implications for clinical care in general practice?

Through reference to children with chronic, moderate-severe asthma in Auckland, this paper seeks to answer these questions from the perspective of community-based practitioners of medical care – specifically, general practitioners (GPs) and community-based paediatricians. What they believe might not reflect the beliefs of children and their caregivers. However, the beliefs of these practitioners underpin their own clinical behaviour. Their standing as professionals gives credibility to their beliefs about health care, and patients and caregivers may not be exclusively able or willing to define aspects of their own reality.[6]

This paper focuses particularly on Maori and Pacific Islanders. Children from these groups may have more severe asthma than do other children;[7] receive GP care less frequently than NZ Europeans when relative need for health care is taken into account;[8,9] and experience delays in getting it.[10] The generalisability of our findings to other cultural groups is considered in the context of implications for managing asthma avoidance in general practice.

Method

Qualitative research methods were used as part of our study of the barriers, as perceived by practitioners and families among others, to children with chronic asthma accessing GP care in Auckland. The methods have been described previously.[11] Twelve informants were selected, of whom 10 had experience in providing GP care, and two were community-based paediatricians. Table 1 summarises the maximum variation sample. Each practitioner gave the first author a personal, face-to-face, semi-structured interview during March–May 2001. On average, interviews lasted 47 minutes (*s*=11 minutes). Questions included, *'How do families cope with chronic asthma in a child?'*, but were revised for different informants and in response to emergent themes and impressions. All interviews were audiotaped with informant consent. Transcriptions were read several times by the first two authors. Using a general inductive approach, they independently and systematically reduced, reassembled and interpreted practitioners' narratives, while making comparisons with relevant literature. Agreed themes were categorised into analytic categories that were generalised to a theory.

Table 1. Attribute profile of practitioners

Practitioner (Pr)	Age	Sex	Ethnicity	Practitioner perspective
1	30–39	Female	Maori	Maori GP care
2	40–49	Male	Maori	GP care
3	40–49	Male	Maori	GP care
4	30–39	Female	NZ European	Maori GP care
5	30–39	Male	NZ European	GP care
6	30–39	Male	NZ European	Adolescent paediatrics
7	40–49	Female	NZ European	GP care and research
8	30–39	Female	Samoan	Pacific GP care
9	70–79	Male	Samoan	Pacific GP care
10	30–39	Male	Tongan	Pacific GP care
11	40–49	Male	Tongan	Community paediatrics
12	60–69	Male	South Asian	New settler GP care

NZ = New Zealand, GP = general practitioner

Results

Patient and caregiver responses to chronic asthma in children were reported by the practitioner sample to include avoidance. This was viewed as a mechanism for coping with distress or, in the absence of a perceived need to manage either distress or positive stress, as a non-adaptive response to no stress (Figure 1). If respondents were representing avoidance correctly, this could help to account for non-attendance for GP asthma care. As non-adaptation, avoidance was suggested to take two forms: normalisation and minimisation.

Normalisation

Some families were reported to perceive children's chronic asthma, even when moderate-severe, as 'normal'. This was suggested to occur particularly among Maori, notwithstanding great diversity within this population. The interviews highlighted four sets of reasons for normalisation, not associated with the occurrence of, and need to manage, distress.

First, some parents or caregivers were reported not to know that their child has asthma. Practitioner (Pr)7 noted that some *'just accept that a wheezy, coughing child is the way a child should be, so they don't give it the priority it really needs.'*

Secondly, normalisation could result from patients and informal caregivers not understanding the seriousness of childhood asthma. One reason, given by Pr3, is that they may experience difficulty distinguishing between bronchiolitis and asthma: *'for the parent or caregiver of the child, that change in the pathological cause of the condition isn't something that's their concern. It's the same thing. The kiddie wheezes, they run around, they're fine.'*

Familiarity is a third explanation. According to Pr4, at a Maori health clinic, *'you get used to your child getting asthma in the middle of the night...and you get used to the child going into hospital... so it's not seen as that severe; it's more a routine part of life.'* She also suggested that caregivers have grown *'used to poor management and have stopped looking for answers'* and some Maori *'see a lot of asthma in their families. It's often taken for granted'*.

Fourthly, said GP researcher, Pr7, *'children's health issues aren't seen as important [by some caregivers]'*, at least relative to other family members' experience of chronic disabling diseases other than asthma or other priorities in daily living. As Pr3 said, *'the squeaky door is the one that gets the oil...a kiddie that wheezes and is functioning normally – still able to run around the place, still able to eat, still able to interact normally – is not a problem.'*

For such reasons, because *'asthma is quite common, it's almost normalised'* (Pr4). As a consequence, *'at the individual level you have a lot of people out there who have just got used to it, got used to poor management and have stopped looking for answers'* (Pr4). Hence, she said, they attend less appropriately for GP care than do families who seldom experience asthma and thus tend to be more easily frightened or worried by its occurrence.

Minimisation

Normalisation was perceived to minimise the significance to patients, and their caregivers of sickness or symptoms. However, practitioners indicated that even those who do not consider asthma to be 'normal' may perceive chronic asthma in a child to have such minimal significance as not to require coping. This process of 'minimisation' was suggested to reflect what practitioners perceived as patients' or caregivers' lack of understanding of childhood asthma, comparisons with others who are more sick than they, and lay priorities.

The last explanation is pertinent to teenagers, among others. Adolescent paediatrician, Pr6, observed that a frequent teenage response to something, such as asthma, *'that marks you out as different or atypical'* is *'to minimise that difference... because of the unconscious need to fit in with peers and be regarded as normal.'* However, according to Pr6, *'I don't think they regard it [minimisation] as coping'* because *'most young people, who have asthma or chronic severe asthma, that I see are young people who don't actually regard it as a big deal.'* They *'see the priorities in their life as fitting in with their mates, having fun, doing the things they enjoy.'* He continued, *'They just see it as not important or not an issue.'*

Also minimising the personal significance of asthma and need for coping is a perceived, organisational tendency among many Maori and Pacific Island people to foster collective rather than individual 'ownership' of sickness and any response. Pr1 and Pr5 explained that these cultural groups function not as individual 'I-selves' but rather as 'we-self' identities. They respond to perceived needs of the family, tribe or village, and nation, although these respective and interacting needs are partly defined by the individuals composing such groups. According to Pr1, the family *'is likely to impact particularly in terms of ongoing care... perhaps less likely if they wake up and Johnny's a bit wheezy at three in the morning.'*

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Discussion

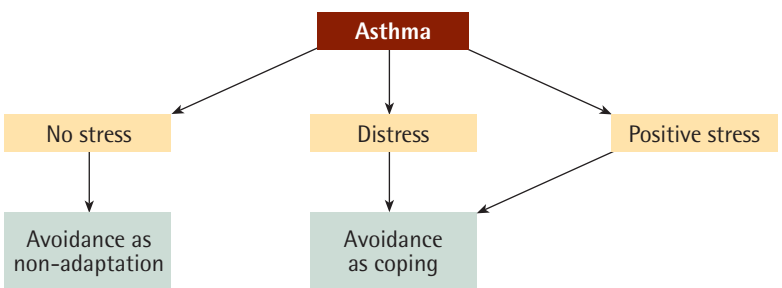
In this study, informants perceived patients' and informal caregivers' avoidance of moderate-severe child asthma as a potentially non-adaptive response rather than necessarily as coping. Whether avoidance signifies coping in a particular situation depends, it was suggested, on whether the avoidance reflects a need to manage emotional distress. According to our sample of practitioners, chronic, symptomatic asthma in children does not necessarily produce distress or positive stress, and so can lead to non-adaptive avoidance of the belief that the symptoms require coping. Such avoidance was said to be manifest in the minimisation and normalisation of asthma symptoms, especially among Maori and Pacific Islanders.

Normalisation is the most prevalent attribution of symptoms in general practice attendees and the population as a whole.[12] Minimisation has been reported among teenagers[13] and might or might not indicate coping, depending on whether the differences, produced by asthma symptoms, cause distress. Some teenagers see asthma as potentially stigmatising,[13] but most were reported in this study not to see asthma as a major problem. Our findings have relevance to collectivistic cultures, including Asians,[14] and go beyond child asthma, where lay persons' lack awareness of the seriousness of illness symptoms, see no need to cope, or both.[11]

Implications for GP care

This paper describes practitioners' representations of how patients view their asthma, rather than direct reports from patients or informal caregivers. However, the representations reported, regardless of whether patients accept them, underpin practitioner behaviour. Against this backdrop, appropriate GP management of avoidance by asthmatic children and their informal caregivers would appear to depend

Figure 1. Conceptualisation of avoidance



on three factors. The first is recognition of why moderate-severe asthma presents in a particular child. The second is detection of whether avoidance, where it occurs, signifies coping or non-adaptation. The third factor is practitioner assessment of the effectiveness of avoidance as a situational response to the asthma, in the context of factors such as the severity and control of this disease.

It may be argued that GPs lack the diagnostic competency to judge psychological processes in patients and caregivers. However, GP care frequently incorporates some form of psychological management and *'there is preliminary evidence from a few studies of the clinical effectiveness of GP psychological management in routine consultations'*.[15] Individual GPs are also capable of improving their own ability to detect psychological distress, using for example the self-directed intervention reported by Howe.[16]

Where asthma does not produce distress, the GP needs to decide how to manage the asthma and non-distressing response. An absence of distress may help patients and caregivers to avoid the onset of asthma symptoms that are due to distress associated with asthma, though not other causes, or manage asthma symptoms without adaptation. However, the severity of the asthma should be a critical influence on the management approach of the GP.

If the asthma is very mild, the GP might not discourage avoidance or even discuss the potential seriousness of asthma as a condition. The GP may believe that information-giving about asthma could have predominantly negative consequences for the child and/or his or her family; it may cause *'such anguish for everybody concerned that it is sometimes accurate to say that it does more harm than good'*.[17] In contrast, moderate-severe asthma is a potentially serious condition, even where it does not cause emotional distress. Because asthma is controllable, GPs have a duty to ensure that patients with asthma of this severity, or their caregivers, are aware of potential dangers of the disease.[18] This is notwithstanding that this awareness could distress patients who avoid distress through not knowing. Here, the GP has a responsibility to offer asthma education and counsel for the primary prevention of distress.

Where avoidance is a coping strategy, the GP may need to help the patient or caregiver manage the asthma and any distress it produces. Avoidance may be functionally adaptive and protective.[19] It may help to remove distress by positively influencing attributes of the asthma,[20] or to manage goals proactively.[5] However, if the avoidance is maladaptive, GPs need to offer education and counsel for the secondary prevention of distress; they should offer information, coping strategies, and help to manage asthma symptoms without significant distress. How GPs manage avoidance depends on their ability to distinguish between, and respond to, its different forms, in the context of knowing patients and caregivers.

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