GP care for moderate to severe asthma in children: what do infrequently attending mothers disagree with and why?

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Objectives. Our aim was to identify and account for areas of disagreement with GP care for moderate to severe child asthma among mothers who infrequently use this care. Identifying and understanding these areas of disagreement has the potential to improve child access to GP care.

Methods. This qualitative study in Auckland, New Zealand, used a general inductive approach to analyse 23 semi-structured, personal interviews during March–October 2001 with samples of 11 mothers of children with moderate to severe asthma, and 12 medical providers (10 in general practice and two in hospital emergency departments). Disagreement was defined by mothers’ non-acceptance or disapproval of aspects of GP care they reported getting for child asthma.

Results. Mothers and providers described four areas in which some mothers disagree with aspects of GP care for child asthma. Contributing to infrequent attendance, the areas are the validity of the diagnosis, the level of service provision, the effectiveness of care and the level of respect from practice staff. These areas revealed three groups of mothers. GP factors contributing to disagreements among mothers were reported to be inconsistent care; information deficits on asthma and individual children; a lack of commitment to identifying the cause(s) and self-management of asthma in children; and an unmet need for asthma management plans that incorporate families’ knowledge, goals and preferences.

Conclusions. Disagreement, among mothers, with areas of GP care for child asthma contributes to non-attendance for this care. This paper identifies opportunities for GPs to keep disagreements to a minimum and facilitate access.

Keywords. Access, agreement, asthma, children.

Introduction

For at least 25 years, the level of agreement between patients and GPs on patients’ problems or needs, and their preferred management, has been shown to be positively associated with outcomes such as adherence to treatments,1 problem resolution,2,3 patient satisfaction,4 avoidable morbidity and economic savings.5 The level of agreement has also been demonstrated to influence attendance for GP care, including screening and immunizations among children,6 in the context of patterns of help-seeking behaviour that involve multiple sources of health care advice and support.7 Mothers, in particular, lead decisions on whether or when to seek GP care for a child,8 and assist adolescent decision making.9 This paper seeks to identify and account for areas of disagreement with GP care for moderate to severe childhood asthma among mothers who infrequently use this care. Problems reflecting these areas of disagreement can then be addressed to improve access to GP care.

Disagreement is defined in this paper by mothers’ non-acceptance or disapproval of what GPs did or did not do for their asthmatic child, where GP (in)action is based on mothers’ reports. Disagreement is not the same as dissatisfaction. Mothers may disagree with aspects of GP care but nevertheless report ‘satisfaction’ if they believe that GPs have not failed in their ‘duty’ or are not
‘culpable’ (because of mitigating circumstances such as time constraints). The significance of mothers’ disagreements emerged from analysis of data collected during our larger investigation into why some children with moderate to severe asthma are not getting GP care in Auckland, New Zealand (NZ). GPs in NZ diagnose and manage most asthma. However, there are wide, unexplained variations in attendance for asthma in NZ general practice. Parents are accessing hospital emergency services, especially out-of-hours, for first contact care of acute presentations that primary care could manage cost effectively. In particular, at the aggregate level, Māori (the indigenous population of NZ) and Pacific Islanders use GP care less frequently than do NZ Europeans, are disadvantaged socio-economically and live disproportionately in Auckland. A focus of this paper therefore is disagreement by Māori and Pacific Island mothers.

Methods
Using a general inductive approach, this qualitative study identified and helped to explain the theme of disagreement from interviews with mothers and providers, on barriers to accessing GP care. The study adopted a post-positivist perspective, which contends that there is one reality, uniquely but not fully understood by each individual. According to this perspective, the role of research is to help people tentatively decide what to believe, through recourse, for example, to insiders’ perspectives.

Sampling
With approval from an ‘Auckland Ethics Committee’, semi-structured interviews were held with 23 informants: 12 providers of medical care, mainly in general practice, and 11 mothers. Tables 1 and 2, respectively, summarize each purposive sample.

The mothers each had a 6- to 14-year-old with chronic (≥3 months), moderate to severe asthma (≥4 attacks in the previous year and/or asthma-associated sleep disturbance or speech limitations). They also reported visiting a GP ≤2 times in the past year because of perceived barriers to accessing GP care more frequently. Children under 6 years were ineligible for inclusion because, in contrast to older children, their GP care is free at the point of contact with the health system. An upper age limit of 14 years was selected to incorporate the perspectives of mothers who have older children, specifically in the middle teenage years. As Table 1 shows, mothers varied by the age of their children. This ensured diversity in the influence of children on decision making about the use of GP care. The sample contains few Māori and Pacific Island mothers because, compared with NZ European mothers, they are less willing to advocate for themselves and challenge authority (see below). Ten mothers were identified from presentations at the Emergency Department of an Auckland children’s hospital with a primary diagnosis of asthma in the year ending 30 June 2001. A further mother was included after she contacted us in response to a newspaper article about our project.

Providers (nine GPs, a community paediatrician working in general practice and two doctors from different emergency departments for children) were interviewed first. They had no known professional relationship with the mothers interviewed subsequently. Providers were identified through personal contacts, and selected to vary by age, sex, ethnicity and, from our prior knowledge, willingness to endorse, or challenge (six providers), the status quo (Table 2). Their perspectives underpin their own behaviour as professionals and may help to account

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<th>Mother ID</th>
<th>Ethnicity</th>
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for patient disagreement.16 Māori and Pacific Island providers were oversampled to reveal insights into what mothers from their ethnic groups may be unwilling to discuss owing to factors such as embarrassment, felt shame and shyness. These feelings describe a perception of social disadvantage (whakama) that discourages criticism of professionals to outsiders, such as researchers.17,18

Interviews
Each informant gave one face-to-face, personal interview. Interviewing ended when the diversity sought within each sample, and data saturation, had been achieved. The first author (SB) conducted all the interviews between March and October 2001, typically at GPs’ place of work and mothers’ homes. The interviewer was a 40-year-old, NZ European. As a non-GP and an experienced researcher working in a University Department of General Practice, he was mindful of the need to interview in a non-judgemental and empathetic manner and to assess and minimize any bias or influence he and the research process had.

An interview guide was used, comprising potential topic questions linked to probes. It focused on barriers to accessing GP care for moderate to severe child asthma. Questions were not asked specifically about what mothers might disagree with regarding GP care. Rather, mothers’ level of agreement with aspects of this care was unsolicited and, as noted earlier, emerged during the analysis phase. Questions posed at the interviews were adapted to each informant and in response to impressions recorded in a field journal immediately after each interview. With consent, all interviews were audiotaped and later transcribed by SB.

Analysis
Transcripts were read several times by two authors. They independently and systematically reduced and reassembled each set of interviews, making comparison with the literature, to identify and account for areas of disagreement by mothers with GP management of child asthma. Salient themes were agreed through discussion, refined using NVivo software, subjected to sceptical peer review and checked by provider informants. It is for readers to assess the transferability of findings using information provided about the study context.

Results
Mothers and providers identified four areas in which some mothers disagree with aspects of GP care for child asthma. Contributing to infrequent attendance, these areas are described below, with explanatory insights from mothers and providers. The areas of disagreement reveal three groups of mothers. Mothers in the first group were well educated and articulate. Mainly professionals and managers, they questioned recommended drug treatments and were interested in complementary treatments such as homeopathy and Butako. The second group were not socially or economically advantaged. Compared with the first, they shared concerns but were less able to explain why and were less committed to complementary treatments. Providers suggested that many Pacific Islanders and traditional Māori form a third group. It includes highly educated mothers who use traditional healing alongside mainstream services, but also Pacific Island immigrants and other ‘poor and dispossessed’ women who have grown up with traditional healing as the norm for them.

Validity of the diagnosis
Some mothers disagree with the diagnosis of child asthma that GPs give them. From group two, mother (M)8 said, “every time you take your kid in there with a bit of a chest it’s asthma” and “when he wasn’t on all the medication, he was fine.” Moreover, “I used to ask them about it . . . ‘Are you sure?’ . . . And he’d go, ‘Well yes, I can guarantee it’s asthma’ . . . but then I took him back to my doctor and he used to say to me, ‘Well, I don’t think he’s got asthma’.” This lack of consistency raised concerns for this mother about GPs’ technical competency, and was, she said, a disincentive to getting GP care for her son’s asthma.

GP informants explained that poor provider continuity and lack of co-ordination of care increase the likelihood of mothers receiving “different messages” [Provider (P)7] about the diagnosis and other aspects of management. Moreover, some GPs might not diagnose asthma...
because, according to P5, “there is no point treating, diagnosing and treating if nothing is going to be done with it.”

This creates “an incredible amount of confusion” for mothers (P7). It enables them selectively to use feedback to reject an unwanted diagnosis and, among other things, cope with fear of asthma: “there is a lot of myth out there about asthma, and . . . there’s a negative stigma attached to the diagnosis of asthma as well” (P2). Hence, some mothers will not admit that their child gets asthma and needs treatment. Other reasons for rejecting the diagnosis were suggested by P1 and P2 to include a lack of confidence by some Māori in Māori providers.

Level of service provision

Overprovision. Mothers commonly disagreed with some of the care that GPs provide for child asthma. From the first group of mothers, M2 questioned GPs’ need to use nebulizers. As a pharmacist, she knew “that you can get your medication just as effectively through a spacer.” However, as P8 explained, “when you have a ‘toy’ you’re used to using and you get the knack of using it effectively, you become more prone to use it than other things.”

Meanwhile, according to M5, “asthmatics take far too much medication . . . it’s better for the body to learn to cope naturally and that’s why I’ve really put my foot down when it comes to using the preventer. I prefer to not even use a reliever.” There was agreement on this point from M8, who said: “I thought, why are you filling him up on all these steroids and pumps if he’s not fully chesty?”

GPs, including P4, acknowledged such concerns about safety. However, they noted a lack of research evidence supporting the use of complementary therapies for asthma, and that these are not substitutes for appropriate drug therapy.

Group one mothers further expressed concern about dosages. M2 was “pretty sure that the latest evidence was not necessarily to just double the dose of the corticosteroid when they had an instant, upper viral infection.” Unconvinced by her GP’s explanation that it “will reduce the inflammation,” she phoned the hospital registrar, who said that the GP’s reported advice “wasn’t related to current information . . . [so] it didn’t inspire my confidence that much.”

Moreover, two mothers in the first group said that they suspect perverse incentives for GPs to prescribe certain items. M5 asked, “Do they have some kind of deal with the manufacturers of the medication to sell it?”. M9 said, “I don’t know if the doctors have a—you know how sometimes a shop just sells a particular item because they get a good discount. I don’t know if that is what the doctors do. I don’t know if that’s what it’s like with asthma inhalers.”

In the second group, mothers likewise expressed concern that inhaled steroids and reliever medications are unsafe. For example, M1 was uncertain that “Ventolin is addictive.” This concern, compounded by inconsistent advice from providers, led her also to question the dosages prescribed. Regarding the use of Ventolin, she reported that “Different doctors have told me different doses to give her. Some will say so many bursts and then another one will say you can give lots of 10. I really don’t like giving her that much.” Women in this group may also “figure that if they don’t use the treatment, then the child hasn’t got asthma” (P2).

Regarding the third group, providers suggested that some Pacific Islanders are reluctant to use inhalers. These Islanders fear “they will end up using it for the rest of their life, and they think this is something that is unnecessary for the child” (P9) or “they have a perception that the inhaler makes it worse” (P10). P7 commented that “often the problem is not with the mother or caregiver that you see but the advice from all of the extended family.” P4 and P10 added that agreement is needed from numerous people, some of whom do not visit the GP with the child. For example, P10 described a recent visit by an asthmatic boy and his father, who said, “my wife wants that’ and I looked at it and . . . I thought that the medicine needed to be altered. But no amount of talking on my part was going to convince this guy because he said ‘. . . my wife said this’.”

Conflicting advice may also come from traditional healers whom many Pacific Islanders visit because “they are not sure about the medicine that is given by the doctor . . . Not very many do admit [to visiting them] but you can see from their bodies; they are stained with herbs and oil.” Samoan GP , P7, said that even “my friends who have been to university all take their children to traditional healers.” She added that it is important to permit Pacific Islanders “to keep their beliefs but selling the fact that they have to accept some of this [GP] treatment, some of the lifestyle changes in order to achieve what we both want, which is better health.”

Spanning all three groups of mothers was a common belief emphasizing treatment, rather than the medical prevention, of asthma. This belief explains some disagreement with the need for inhaled corticosteroids. Thus, as one GP admitted (P7), “with something like a preventer, I don’t have a very high success rate . . . Once it’s better, it’s discarded. It’s very hard to understand the concept of a chronic illness and the need for ongoing medication in the face of wellness.”

Underprovision. This theme was associated with the first group of mothers, from which two women criticized GPs for failure to identify and treat the cause of asthma in their children. According to M4, who has a Master of Science and is studying homeopathy, GP treatment of asthma is “like putting a bandage for a tear . . . you’re giving her the steroid, you’re keeping it under control, you’re not really treating the disease.” M5 offered a similar perspective. However, P4 believes there is large
variation in the care provided by GPs, some GPs helping mothers to find out what triggers asthma in their children where the causes are unclear. P4 also identified time constraints to increased effort by GPs at identifying causes.

M5 criticized GPs for not prescribing oral steroids on request. She stated, “I’ve asked for it and they’ve said, ‘We don’t think it’s necessary at this stage’. They’re reluctant to just prescribe it unless the kid’s practically on death’s door.” However, GPs expressed their concern that some patients will use oral steroids inappropriately and not return. M5 also questioned the perceived delay in doctors using a nebulizer. M4 added, “sometimes they give the oxygen first before they give the nebulizer, which I find takes longer to kick in. For me it’s a case of nebulizer first and then maybe the oxygen after that.” In contrast, M2 said that “if I go into . . . [the hospital], I can get their oxygen saturation levels measured and from the reading on that, I’ve got a pretty clear idea of whether she is going to need oxygen or not for the night, and I can’t have that done at the GPs.”

M9 disagreed with her GP’s failure to offer her son a spacer: “The spacer’s fantastic. It’s the first time we’ve had one and they gave us one at the hospital. Why hasn’t the GP given us one?” Added M5, “They’re not handed out. They’re not even offered [for us] to buy them.” A key reason, suggested P2, is that NZ GPs do not receive spacers free of charge for patients over the age of 6 and “are not in the business of selling things.” M9 was also critical of GPs for not checking her daughter’s inhaler technique and not measuring her peak flow.

Effectiveness of care
All three groups of mothers, and providers, identified a perception by some mothers that aspects of GP care for child asthma are ineffective. This perception summarizes the foregoing problems and the belief that some GPs are not experienced or good with asthma (M5 and M9) and/or children (M1). According to M9, “if the doctor had given us the right information in the beginning I don’t think she [her daughter] would have ended up in hospital.” Yet, this mother continues to take her daughter to the same GP, “only because we go for other things.” M11 expressed concern about locum care in general practice. She now avoids it because on several occasions it has been “substandard for my children.”

Because of such concerns, some mothers are uncertain whether to go first to a GP or to emergency services for asthma attacks. M4 said, “I’d rather go to somebody who is going to arrest it or do something than put her through all these nebulizers and this and that, which is just prolonging the time before I’m sent to a hospital.” Providers noted that use of hospitals for first contact care occurs especially among Pacific Islanders. Hospital doctor P11 estimated that, at his Emergency Department, as many as one in every three child asthma presentations could be managed cost effectively in primary care.

For his different hospital Emergency Department for children, P12 reported a ratio of one in six.

Respect from practice staff
Some mothers in all groups perceived a lack of respect from practice staff. For mothers in group two, this was felt in terms of how staff relate to them. For example, M1 said, “I don’t feel that she’s speaking to me at all. You could be a bug under a microscope. She speaks to you purely from a scientific view.” In contrast, mothers from group one said that, too often, their views were not taken seriously during decision making about treatments for child asthma. According to M9, her GP will not prescribe the type of preventer requested by her 14-year-old daughter. M5 agreed that “What is frustrating for the parent is that you don’t get any say in it.” Similarly, from M11: “I know my children well . . . and I don’t believe that’s listened to or even acknowledged. I find that very frustrating.”

Aware of such concerns, providers added that traditional Māori and Pacific Islanders may disagree with GP care that responds to the needs of the child rather than what is best for the family—which is defined, in part, by what is best for the child. Providers, such as P7, said that it is difficult for GPs to overcome whakamā in patients, and the unwillingness of many of these people to express disagreement to you. Thus, she said, “one of the things that we work very hard on in the clinic is to teach people that it’s OK, that I’m not going to be offended.”

Discussion
Quantitative studies have provided “some evidence that patients and health professionals often do not agree on treatment preference in the areas of cardiovascular disease, cancer, obstetrics and gynaecology, and acute respiratory illness.”19 (p. 139). More recently, Vedsted et al.20 reported that the priorities of patients and GPs in Denmark are highly correlated. The present, qualitative research has identified, and suggested reasons for, areas of disagreement by Auckland mothers with GP asthma care for children. Mothers and providers suggested that the areas which discourage attendance relate to the validity of the diagnosis, the level of provision of care, the effectiveness of care and the level of respect from practice staff. These areas revealed three groups of mothers: well-read mothers who tend to be critical of mainstream care; ‘ordinary’ mothers with similar concerns to the first group but less ability to explain why; and Pacific Island and Māori mothers who engage with mainstream and traditional health services, or who live solely within the framework of their traditional culture.

Mothers and providers suggested GP factors that help to explain the disagreements. These factors reduce to
four, all challenging the quality of care provided. The first is inconsistent care, as reflected, for example, in the diagnosis and in dosages prescribed, in the context of a wide range of lay and professional sources of advice. Reid et al. reported only minor differences between the criteria used by NZ and UK GPs to diagnose asthma in children aged under 5 years. However, mixed messages from GPs on diagnosis and treatment were reported in our study. These can confuse mothers, as shown for the second group; encourage mothers to question provider competence; and permit mothers to accept only the information they can cope with easily. A related problem occurs where different caregivers present with a child at each GP visit. This lack of ‘patient continuity,’ which is common among Pacific Islanders, increases the likelihood that information will be understood differently, even if consistent.

Secondly, disagreements resulted from GPs appearing to lack information in two areas. One was the best scientific evidence on asthma management. For example, M2 observed that a metered dose inhaler and spacer and mask deliver drugs to the lungs at least as effectively as a nebulizer, M9 noted an unmet need for GPs to demonstrate, review and, if necessary, correct the inhaler technique when asthma control is poor. Reflecting poor continuity, and poor co-ordination, of care, the other area of information deficit was the needs of individual children.

The third source of disagreement was a perceived lack of commitment by some GPs to identifying the cause of individual children’s asthma and enabling self-management by families through asthma education and the provision of spacers, peak flow meters and oral steroids. Mothers tended, however, to favour treatment of asthma rather than its primary prevention through inhaled steroids.

A fourth, related source of disagreements by mothers was a tendency for GPs to promote a Western medical model without clearly explaining and permitting questioning of it. In the third group, this exacerbates, and is compounded by, whakamā, such that non-attendance may reflect disagreements that mothers cannot verbalize to GPs. Associated with lack of open communication was an unmet need to demonstrate respect for mothers, for example when developing treatment plans. Consistent with previous findings, this matters because, for example, as M9 noted, an effective inhaler is one a child prefers to use and can use correctly.

Strengths and limitations
A strength of this research is its inclusion of an unusual subgroup: infrequently attending mothers for GP care of child asthma. GPs typically assess their own performance by considering how well they do with the patients they see, not those who tend not to return. It is not possible to move from our analysis to recommendations about how to manage all visits for child asthma. However, insights were offered into areas of disagreement that may need to be avoided.

No attempt was made to enumerate prevalences of these areas or to assess their relative importance in limiting access to GP care. These are avenues for future research using quantitative methods. Nor was any attempt made explicitly to ascertain what mothers do that contributes to GP disagreement or to verify mothers’ reports of GP behaviour. Whether these reports describe what GPs actually did matters little here because the beliefs that mothers have can be expected to underlie their own behaviour as help-seeking agents for children.

Implications
Some mothers will always disagree with aspects of GP care. However, there is scope usefully to increase their level of agreement. Strategies to improve the consistency and appropriateness of information that GPs offer include explaining why children need to attend the same GP(s) in one practice with the same caregiver(s) each visit; use of evidence-based clinical guidelines; and increased co-ordination of care through information systems such as electronic patient records.

Meanwhile, GPs should emphasize to mothers that absolute answers do not necessarily exist, and so “wide variation in treatment choices can remain perfectly consistent with medical knowledge” (p. 61). Increased agreement, reflecting intended variation, will also occur through open communication. This includes negotiated management plans that value and incorporate parents’ knowledge, goals and preferences, which are “largely unrecognized by guidelines.”

In the face of time, and other, constraints, it is all too easy, but self-defeating, to lose sight of the attributes that define GP care and why mothers should use it. However, while GPs can increase agreement, so too do mothers have responsibilities to GPs. For example, while GPs have an ethical duty to declare conflicts of interest in decision making, the obligation is on mothers, we believe, to articulate any suspicion of perverse prescribing incentives.

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References


16. Devers K. How will we know “good” qualitative research when we see it? Beginning the dialogue in health services research. *HSR: Health Serv Res* 1999; 34: 1153–1188.


