

Expectations of patients and parents of children with asthma regarding access to complementary therapy information and services via the NHS: a qualitative study

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Abstract

Objective To explore the expectations of patients and parents of children with asthma regarding access to complementary therapies via the NHS.

Methods Fifty semi-structured interviews with adults and parents of children with asthma, from a range of health-care settings, including users and non-users of complementary therapies. Interviews were recorded, transcribed verbatim and the data were analysed thematically.

Results Thirty-one patients were using complementary therapies for asthma, six were using complementary therapies for other health problems and 13 were non-users. Various therapies were used for asthma, most commonly homeopathy and breathing techniques, predominantly outside the NHS. Two broad themes emerging from the data were expectations about access to *information and knowledge* about complementary therapies via NHS health professionals, and expectations regarding access to complementary therapy *services* via the NHS. As a minimum, the majority of participants wanted NHS health professionals to be more 'open' towards and know more about complementary therapies than their patients – perceived as not currently usual. Most were positive about greater NHS access to complementary therapy services, for enhancing patient choice, improving equality in access for less affluent patients and facilitating patients' self-help. Participants who were highly sceptical about complementary therapies argued that lack of scientific evidence of effectiveness prohibited the need for greater complementary therapy knowledge or service provision within the NHS. Alongside their expectations, patients and parents expressed realistic views about facilitators and barriers to greater access.

Conclusions While health service planners and providers often express reservations about the value of complementary therapies, it is important to take patients' preferences into account if policy discourses regarding patient-centred care and choice are to be realized in practice.

Introduction

An increasing number of patients in the UK are using complementary therapies, especially for chronic health conditions. A recent survey of adults in England and Wales indicated that 10% see a complementary therapist in any 12-month period and 40% have used complementary therapies during their lifetime.¹ Most complementary therapy use takes place outside of the NHS, either in private consultations with complementary practitioners or through patients' self-treatment with over-the-counter complementary products.

There has been heightened attention to the potential role of complementary therapies *within* the NHS recently.^{2,3} Complementary therapies are slowly moving up the agenda in certain areas of health policy, such as the Department of Health's patient choice agenda, which suggests that the NHS should work towards a framework for providing patients access to complementary therapies.⁴ The secretary of state for Wales and Northern Ireland, Peter Hain, recently recommended that complementary therapies should be more widely available on the NHS.⁵ A growing number of general practices are providing some form of complementary therapies, although funding is often *ad-hoc*, uncertain and not sustained long-term.⁶ In 1995, an estimated 39% of general practices provided some access to complementary therapies, while a repeat survey in 2001 estimated that this had increased to one in two practices in England – this was attributed to increased in-house provision.⁷

Some research has explored health professionals' views of NHS access to complementary therapies. In a small survey of primary health-care workers in Northwest London, 83% had previously referred (or influenced referral) for complementary therapies, the main reason being

patient request (68%). There was a significant interest in more training or information on complementary therapies (66%) and only 6% were against any integration of therapies into mainstream primary care.⁸

What are patients' views about access to complementary therapies via the NHS? A number of studies have investigated patients' decision-making about complementary therapies and motivations for use.^{9,10} There has been some evaluation of patients' satisfaction with NHS complementary therapies in settings where there has been some integration of therapies into mainstream services. In a qualitative study, primary care patients reported complementary therapies as ameliorating their condition and valued their active role within the therapeutic relationship.¹¹ A study of patients attending a complementary therapy outpatient clinic in London found that patients wanted wider availability of complementary therapies on the NHS,¹² and were coming to that service with a range of expectations, including the provision of symptom relief, a holistic approach, improved quality of life, and information and self-help advice about their condition.

Until now there has been a lack of in-depth qualitative research on patients' expectations of NHS access to complementary therapies that includes patients from a range of health-care settings – both those that provide complementary therapies and those that do not, both NHS and non-NHS. This is needed, in order to tap into the broad range of expectations that may be held by patients, in order to inform future service planning, particularly with the emergence of practice-based commissioning in primary care.¹³

It seems appropriate to focus on patients with a chronic condition, given the rise in complementary therapy use for chronic conditions. We chose to focus on asthma, as this is the most

common chronic condition in the UK¹⁴ and has received limited research attention with regard to patients' use of complementary therapies. This is perhaps because conventional treatment for asthma is seen to be generally effective, whereas other chronic conditions are less well helped by conventional medicine. However, surveys suggest that a significant proportion of asthma patients are using complementary therapies.^{15,16} Previous studies of asthma patients have primarily investigated their views and beliefs about conventional treatment,^{17,18} for example, identifying patients' concerns about oral steroids.¹⁹ Limited attention has been given to asthma patients' interest in complementary therapies and their potential role in self-management.^{19,20} A detailed qualitative investigation of asthma patients' expectations about NHS access to complementary therapies remains to be undertaken. The present study aims to address this issue.

The broad purpose of the study was to explore asthma patients' and parents' views and use of complementary therapies. Within this, a number of more specific research questions were identified. Because of increasing debates about NHS access to complementary therapies, these questions included: 'What are the expectations of patients and parents of children with asthma regarding access to complementary therapies via the NHS and why do they hold these views?' These questions are the focus of this paper.

Methods

The study took place in Bristol (south-west England) and was approved by the Central and South Bristol Research Ethics Committee. Qualitative methods were chosen as we sought to answer 'What?' and 'Why?' questions, exploring patients' and parents' perspectives in depth and the rationales they gave for their views.

Participants

Maximum variation sampling techniques were used to identify a range of patients and parents of children with asthma from both NHS and

non-NHS settings, including non-users and users of a variety of complementary therapies. Sampling comprised various stages. First, two general practices were selected: one in an affluent area of the city with no NHS provision of complementary therapies but potential access to several private complementary clinics; the other in a relatively deprived area of the city with limited access to certain subsidized complementary therapies via the practice. In each practice, a random sample of 100 patients (both adults and children), with an asthma diagnosis, and a prescription for asthma medication in the past 12 months, were selected. Patients and parents of the children were sent a screening questionnaire on complementary therapy use and asked to indicate whether they would be willing to be contacted about an interview. From the responders, a heterogeneous sub-sample was selected for interview, to include a range of ages and gender, both non-users and users of various complementary therapies. In the first practice, 32 people responded (32%), with 28 agreeing to be contacted for an interview and 23 were actually interviewed. In the second practice, 22 people responded (22%), of these 17 agreed to be contacted, and 10 were actually interviewed. In both practices, not all those who agreed to be contacted were interviewed, primarily because of saturation of data from those not using complementary therapies.

After preliminary analysis of data from the primary care participants, we chose to approach some patients and parents from a further three settings: an asthma outpatient clinic at a children's hospital, an NHS homeopathic hospital and private complementary therapists. At this later stage of sampling, complementary therapy users only were targeted because of relative data saturation from non-users. We chose these settings because we wanted to ensure greater representation of views of parents who were regularly accessing secondary care for their child's asthma, patients who were accessing an NHS-provided complementary therapy service (homeopathy) and those who were accessing private complementary therapists rather than self-treating or purchasing over-the-counter complementary

Box 1 Settings with participants recruited

General practice in an affluent suburb with potential access to private complementary therapy clinics
23 participants
11 adult patients (4 males, 7 females)
12 parents (all mothers)
7 complementary therapy users, 16 non-users
General practice in a deprived inner city area with access to subsidized complementary therapies via the practice
10 participants
6 adult patients (1 male, 5 females)
4 parents (1 father, 3 mothers)
7 complementary therapy users, 3 non-users
Outpatient respiratory clinic at an NHS children's hospital
5 participants
All parents (1 father, 4 mothers)
All complementary therapy users
Outpatient clinic at an NHS homeopathic hospital
5 participants
All parents (5 mothers)
All complementary therapy users
Private complementary therapists
7 participants
4 adult patients (1 male, 3 females)
3 parents (all mothers)
All complementary therapy users

products, as these were some gaps that we identified in the initial primary care sample. Parents and adult patients using various complementary therapies were identified by practitioners in those settings, given information about the study and asked if they were willing for the researcher to invite them to take part. All those identified were willing to be approached and participated – five parents from the asthma outpatient clinic, five parents from the homeopathic hospital, and seven patients and parents from private complementary therapists. Box 1 provides more detailed information on the recruitment settings and the participants within each.

Data collection

Fifty semi-structured interviews were conducted by AS, including 21 interviews with adult patients and 29 interviews with parents of children with asthma. Thirty-one participants were

complementary therapy users and 19 were non-users. Written informed consent was obtained from each participant prior to starting the interview. Interviews took place in participants' homes, lasting between 30 min and an hour. A topic guide was used, with flexibility for participants to introduce issues of importance to them and for the researcher to introduce new lines of questioning derived from preliminary analysis of earlier interviews. Broad topics included patients' and parents' views and experiences of NHS asthma care, their views and experiences of complementary therapies in general and specifically for asthma, and their views about appropriate health-care settings through which to access complementary therapies. This paper focuses on the latter topic. All interviews were recorded with a mini-disc recorder. The digital audio files were transferred to a secure University computer and transcribed verbatim by a research secretary.

Data analysis

Preliminary data analysis commenced alongside early interviews to inform questioning in later interviews. The data were analysed thematically, guided by the principles of constant comparison,²¹ where data elements are continually compared in an iterative process to generate core categories and themes. Individual transcripts were read and re-read, from which an initial coding framework was developed. This framework was added to and refined, with coded material regrouped as further transcripts were coded, with gradual building of broader categories and themes. The full range of transcripts was then compared, to identify confirming and disconfirming perspectives across all the participants, giving attention to minority as well as majority views. AS led the analysis, but a sub-set of transcripts were also coded by ET and DS, to add breadth of perspective and credibility to the data interpretation. The three authors discussed the extent of agreement and variation between the three sets of coding for each transcript, and agreed the broad coding framework to be used across all transcripts.

Results

Participants were using a range of complementary therapies for asthma (see Box 2) and were primarily accessing these outside of the NHS, with the exception of a minority who were using NHS-provided homeopathy at the homeopathic hospital, accessed primarily via a referral from their general practitioner (GP). A range of themes emerged from the interview data relating to the variety of questions of interest within the study. However, we will focus here on two broad emergent themes relevant to questions about patients' and parents' expectations of access to complementary therapies. The first theme is expectations about access to complementary therapy *information or knowledge* via NHS health professionals. The second theme is expectations regarding access to complementary therapy *services* via the NHS. Each theme contains a range of sub-themes. Data supporting each sub-theme are presented in Boxes 3–10. Participant identifiers indicate whether they are patients or parents and if they are complementary therapy users. The data presented reflect the full range of expressed views.

Box 2 Complementary therapies used by participants for asthma

Homeopathy	Massage
Breathing techniques (e.g. Buteyko Method)	Flower remedies
Herbal medicine	Relaxation
Yoga (including yoga breathing)	Acupuncture
Osteopathy/cranial osteopathy	Aromatherapy
Visualization/guided imagery	Chiropractic
Nutritional therapy (and general changes to diet)	Kinesiology
Reflexology	Bowen therapy

Expectations of access to complementary therapy information or knowledge via NHS health professionals

What attitudes towards complementary therapies do patients and parents expect health professionals to have?

The majority of patients and parents (both non-users and users) expressed a basic expectation that health professionals would have more 'openness' to complementary therapies than is currently the case (see Box 3). This was driven by the hope that health professionals would give due consideration and priority to patients' preferences and choices regarding their treatment, whether conventional or complementary.

While not personally interested in complementary therapies, non-users often identified the need for health professionals to be sympathetic to the wishes of those patients and parents who were. Some users had experienced negative reactions from their health professionals regarding their complementary therapy use and desired professionals (GPs especially) to have greater respect for patients' and parents' informed choice about complementary therapies.

With regard to their conventional asthma treatment, while most patients were satisfied with the way treatment choices had been made, some expressed concerns that they had experienced little engagement by health professionals with their anxieties about aspects of conventional treatment. For example, a mother expressed how her GP had disregarded her strong concerns about the side effects of steroids that she believed her son was experiencing. Such anxieties about conventional treatment were

Box 3 What attitudes towards complementary therapies do patients and parents expect health professionals to have?

they should keep an open mind on it (complementary therapies) yes. If they're in the business of treating the whole person, yes they should (AA18, adult male, non-user)

they can't know everything in fairness...but don't decry something if you know nothing about it...I don't think there's enough open-ness for people to make their own decision...Perhaps it's asking a lot...for a doctor or a nurse to be able to say 'Well, this person has thought about it, has found out about something, is telling me that that's their informed choice and therefore I've got to respect that'...I would like to see much more openness to alternatives (HY01, mother, CT user)

Box 4 How much knowledge about complementary therapies do patients and parents expect health professionals to have?

I'm taking the viewpoint of a scientist and therefore I think that doctors should have their minds full of proper medical stuff and has been scientifically validated, and shouldn't have to worry about learning stuff that is unproven, untested and may or may not work...why take doctors out of their normal surgeries and give them training courses on some of these things which I consider to be quackery (AA14, adult male, non-user)

It would be fantastic if you went to your GP and they knew about all these things plus all the conventional stuff as well. That would be brilliant! But I don't expect them to (AC06, mother, non-user)

I would certainly expect them to have a much greater knowledge than a lay person would of complementary medicine, so at least they could say, 'Well, why don't you try this?' 'Have you thought of this?' (AC18, mother, non-user)

you can't actually expect them (GPs) to just know it all but I think that if a client or a patient comes in and says 'Well I've heard about such and such', instead you will have access to good information, reliable information that they can then go to and come back to that client and say 'Well yeah that was really interesting and actually...these studies have been done on this and the overall verdict at the moment on balance is this' (AC10, mother, non-user)

I'd expect the person delivering my primary health care to know all the options and be able to discuss them with me...to be knowledgeable of all the options and sympathetic to my view. So I would expect, if inhaler dependence was increasing, then I would want to know if there was something that I could do, perhaps the breathing therapies, that would help me without having to resort to inhaling something to open my airways (AA53, adult female, non-user)

AA26: I think they've got very little awareness of different therapies, 'cos I went to talk to them about Buteyko and they really didn't know much about it.

AS: What would you hope for or expect in terms of the levels of awareness?

AA26: Well I would hope that actually they would explore all possibilities but they're busy people...they certainly don't contact you and say 'Have a look at this, it might be worth a try'...They wouldn't stop you doing it, but they don't say unless you push and ask, they wouldn't suggest it (*adult female, non-user*)

No-one ever really knows much about complementary therapies unless they've had some sort of experience of it or they are interested in finding out more...it tends to be to do with the company you keep more than the sort of knowledge being available...you find out about it because you have friends who have said 'Oh I went to this person', Oh what sort of rubbish is that?' and finding out about it yourself, it's not something that's widely taught (BA35, adult female, CT user)

I think they should know a bit more...give you a bit more guidance about the food and nutrition side, and the vitamins, because there does seem to be links with certain foods and avoiding certain food groups, that could assist with asthma...and I think things like the breathing methods...that would be really useful for a person with asthma, to be able to really manage and control their breathing (BY13, mother, CT user)

usually an important factor in participants' turning to complementary therapies.

How much knowledge about complementary therapies do patients and parents expect health professionals to have?

Patients and parents expressed a range of expectations regarding health professionals' knowledge about complementary therapies (see Box 4). These included participants who did not expect health professionals to know anything, through to those who wanted detailed knowledge and felt that complementary therapies should be a part of doctors' and nurses' initial

education or professional development. At one end of the spectrum, those who were sceptical about complementary therapies argued that doctors have enough to learn without learning about 'quackery', while others thought that it would be good if health professionals acquired greater knowledge of complementary therapies but did not expect this.

As a minimum, most participants expected health professionals (e.g. GPs, asthma nurses) to have greater knowledge of complementary therapies than their patients – perceived as not currently the case. They desired health professionals to have some awareness of and access to

Box 5 What are the facilitators and barriers to health professionals gaining more knowledge of complementary therapies?

Depends really what they believe in themselves isn't it, if they believe that alternative therapies work then they'd probably refer you...some doctors you talk to and you know as soon as you say you've tried anything different, then the door's shut in your face (BY07, mother, CT user)

I think certain doctors would be open, perhaps the more modern ones rather than the old traditional style perhaps...depends if they're open to change...it depends what kind of clientele you've got as well (AA40, adult female, CT user)

they need to know everything about everything which they can't...the fields get bigger and bigger, it gets more and more difficult. So either you have primary care staff who become more specialised with their own very little narrow areas of interest, but there's a huge danger because GPs are GPs for good reasons, they're the gatekeepers and they're the ones who have got to look at the whole person and not just focus down on specific problems and so I think if they become this is the GP who does this type of problem, they can become very forgetful about the whole person aspect of it maybe (AC10, mother, non-user)

Box 6 What types of evidence about complementary therapies do patients and parents want health professionals to take account of?

Not just doctors, but most people I know who are scientists are very much evidence based and unless you've had a peer-reviewed study which says...yes it's been demonstrated...they will say 'Well, where's the evidence?' Unless it's been published in the BMJ...they'll say 'Well there's no evidence' (AA31, adult female, T user)

I think GPs are too tunnel visioned. I don't think their prepared. I don't know whether they're afraid of looking at something that they don't understand. I had to take my daughter to the doctor the other day and I asked her about something and she said it hasn't been scientifically proven and I said, 'Well, how can you scientifically prove everything when you've just said to me that the body is the most complex thing there is? Surely you can go on experience and other people's knowledge without having to scientifically prove everything?' I think that is a big stumbling block (HY01, mother, CT user)

high quality information about complementary therapies (e.g. via up-to-date databases), in order to advise interested patients. Increased patient interest in complementary therapies was given as a key reason why health professionals should know more about the subject.

At the other end of the spectrum, a minority of patients and parents (both users and non-users) expected health professionals to have detailed knowledge of complementary therapies, alongside the full range of conventional treatment options. For example, to be able to discuss non-drug self-help options for asthma (such as breathing therapies) if patients or parents had concerns about steroid-based medication, or if dependence on medication increased.

In terms of their actual experiences, participants commonly experienced health professionals as knowing little about, and rarely discussing, complementary therapies in consultations unless initiated by patients and

parents. Several felt that health professionals would be sceptical if they tried to discuss complementary therapies. Some perceived an absence of formal opportunities for NHS staff to learn about complementary therapies, noting that informal personal contact with people who have used complementary therapies, and personal interest in or experience of therapies, are the routes by which most people (the public and health professionals alike) gain such knowledge.

Acknowledging the unlikely situation that all health professionals will be knowledgeable about complementary therapies, some participants suggested that particular professional groups could have greater information to advise interested patients. Nurses (e.g. practice nurses, specialist asthma nurses) were especially identified. For example, one patient who was a nurse herself perceived that many practice nurses would welcome opportunities to learn about alternatives to drug treatments, and be a source

Box 7 Do patients and parents expect NHS access to complementary therapy services and if so, how?

I think it would help to be on the NHS 'cos obviously that helps the greater number of people to get to that, because obviously it's not cheap, alternative therapy. But I wouldn't be surprised if it wasn't, it's not something that I expect the NHS to offer... 'cos I think the NHS is kind of stretched as it is, to be stretched even more, what would suffer in order to offer this as well? (AA36, adult female, non-user)

I think the options should be there, preferably, especially if you're a bad sufferer, I think the options should be there for people, great choice, definitely (AA40, adult female, CT user)

Father: if they (patients) could get referrals from a doctor and the national health pay for it, yes fantastic, it might open up to a lot more people as well.

AS: When you say open it up, what might stop people from using these therapies?

Father: I think finances come into it a lot, we're fortunate we've got a way around it, but there's an awful lot of people especially in this area, there's a lot of one-parent families, low paid people, they may not be able to afford it. (BY07, CT user)

I definitely think the things that have got a proven effect on a large number of people, and I'm thinking here of the chiropractic, osteopaths, acupuncture, those things I think would be a good idea because... I really don't feel it's a good idea to pump people full of drugs just to help with the pain relief... Especially with things like backache, where from the experience of people I know, there doesn't seem to be many solutions (AA53, adult female, non-user)

AS: Some people talk about whether these kinds of alternative therapies should be available through their doctors, what do you think about that?

BA11: That is a good idea but for people that really need it otherwise people would be taking advantage. People that are in need, like severe asthmatics or old people... otherwise people would take the mickey for things like that (adult female, CT user)

(breathing techniques) actually sounds feasibly logical, unlike some of the others... that seems to have some scientific basis behind it whereas some of the others don't... the only one I think we should be able to access is the breathing therapies because the rest I think are more quackery, and I don't think people should pay for stuff that is quackery... until some of these techniques are actually proven to work by proper double blind scientific tests in a large, large groups then I don't think the public nation should fund it (AA14, adult male, non-user)

obviously now under present levels of funding there's no way the NHS can possibly pay for everything... but we also know plenty of things that are done under the medical model that are only tenuously based on hard evidence... So... as part of evidence based practise, there is no reason to right off alternative based medicines as part of what the NHS provides (AC10, mother, non-user)

of patient-friendly information on complementary therapies. Therapies that patients and parents especially wanted health professionals to know about for asthma were breathing techniques (e.g. the Buteyko Method) and nutritional therapies, for example dietary factors that may contribute to asthma.

What are the facilitators and barriers to health professionals gaining more knowledge of complementary therapies?

Most patients and parents recognized that an individual health professional's willingness to gain knowledge of complementary therapies depends largely on personal interest and belief in

complementary therapies (see Box 5). Without personal interest, professionals are unlikely to seek information or pursue training in this area. Participants often perceived that younger or more 'modern' generations of doctors are showing increasing interest in complementary therapies compared with older more 'traditional' doctors. The particular patient population served by the doctor was seen as an influential factor – if a doctor's patients are demanding information on and access to complementary therapies, this might exert some pressure to increase their knowledge base.

Patients and parents recognized the demands on doctors and nurses in terms of the ever-

Box 8 Allocation of limited NHS resources: would complementary therapies be a resource drain or a long-term resource saver?

Don't waste money, there're more necessary things in the NHS than giving people complementary medicine, definitely...not on the NHS, no, if they want to do it then pay for it for god's sake, I don't see why I should (AA18, adult male, non-user)

The thing that I would be a little bit worried about is devoting resources to it (complementary therapies) when there are clear needs for conventional medicine that are unfilled...I think it would have to be carefully balanced but I do think it shouldn't be something that's just available for people who are able to afford the luxury of trying it (AA53, adult female, non user)

The advances in medical science and technology are such that there's no way that the NHS can possibly keep pace and use all the facilities it's got to treat all the people it would want to treat, it would swallow up the entire national budget. So therefore there's got to be some selectivity in it...the therapies that I've said I would regard as more medical, I could see that there was an argument for bringing them into the NHS but whether the NHS could actually afford it without cutting out other things? (AA10, adult male, non-user)

I think something like learning how to control breathing, which I really do think has been the one thing that has helped me more than anything else, I'm surprised that things like that aren't available, because say you had someone to teach you to control your breathing...how much would that compare to the cost of a prescription? (AA31, adult female, CT user)

I actually think in the long-term they (complementary therapies) would save money, because I think then an awful lot of problems could be addressed before they become a problem, which is why we go to a chiropractor once every 6 months...and if before the 6 months something happens, I phone them and we go and see her. The old adage that prevention is better than cure has got to be right...I think they should be available because, long term, I still feel it would actually save the NHS money, because those people are going through the NHS and ending up possibly with operations and injuries and illnesses that could have been prevented or lessened using alternatives which they can't afford, but if it was on the NHS so that they could afford it, you wouldn't then need the treatments further down the line...perhaps diet-wise aswell, the nutritionalists and the like (HY01, mother, CT user)

Box 9 Motivators for greater NHS provision of complementary therapy services: patient empowerment and self-management

I'd heard about (Buteyko)...I just felt it would be nice to have something that he could do that would be a positive thing...something that he could do that would empower him in a way, which it did seem to do (DC05, mother, CT user)

I'm dependent on medicine, and...I didn't really want to be dependent on it, so I've tried to come off that and I've tried other things...I've cut out milk and wheat, and I've been to see a homeopathic doctor (CA02, adult female, CT user)

I do feel a bit let down by the medical profession...the automatic response is to write a prescription, but I just wish that they would maybe work more closely with say counselling services or people who do relaxation therapy or hypnotherapy or meditation or anything that kind of gives you...the tools to control your life (AA31, adult female, CT user)

I think that often western medicine just treats the symptoms, it doesn't treat the cause and I feel that if only they could offer this it would make other, you'd have less people calling in at the surgery when it had got a lot worse; you'd nip the thing in the bud (AY29, mother, CT user)

expanding knowledge base they are expected to have and their increasing administrative load. These were seen as barriers to knowledge acquisition about a peripheral area of practice such as complementary therapies. Some acknowledged a tension for primary care staff (GPs in particular) between being good generalists, whilst increasingly being expected to have specialist knowledge in particular clinical areas,

which could perhaps prevent them from considering 'the whole person'. Others noted the potential congruence between a concern for the whole person within primary care and the 'holistic approach' of several complementary therapies – they speculated that this might attract primary care professionals in particular to complementary therapies, to address the broader dimensions of patients' health problems.

Box 10 Barriers to greater provision of complementary therapies within the NHS: dominance of pharmaceuticals, limited medical sanction and a lack of political will

It would be nice to think that they're looking for a way not to use drugs, but drugs are quicker aren't they, and they get people off their books and out of the waiting room, so I can see why they do it...it would be good if they had the time to be looking beyond the standard 'I know this drug works, let's use it' (AA26, adult female, non-user)

I just can't get my head round why doctor's surgeries or...I understand pharmaceutical companies won't have any involvement because they don't get any money from the drugs, but I really think Buteyko should be offered through the surgery (AC09, mother, CT user)

I think there is a lot of resistance (to complementary therapies). I think GPs are probably the most resistant and I am very cynical because I do wonder how much of it is because it's linked to back-handers, for want of another word, which isn't necessarily illegal or whatever, but back-handers from drug companies hold too much power. I think they hold too much influence (HY01, mother, CT user)

it would be good if it (complementary medicine) was available at the doctor's surgery it would be good because it would mean that the medical world was sanctioning it. That's a long way off I would have thought (AY16, mother, CT user)

for it (complementary medicine) to be taken on in a health authority it will take political will, and that's never going to happen, because they need quick whims that they can evaluate within an electoral period...and that's never going to happen, it would take 10 years to try it and then probably 5 years to evaluate it (AA31, adult female, CT user)

What types of evidence about complementary therapies do patients and parents want health professionals to take account of?

Two types of 'evidence' emerged within patients' and parents' accounts of their expectations regarding health professionals' attitudes towards and knowledge of complementary therapies (see Box 6). These were scientific evidence of effectiveness and patients' experiences of complementary therapies. Some participants perceived certain tensions between the two, particularly regarding the relative value that health professionals give to each.

The importance that health professionals attach to scientific evidence and the evidence-based framework in which they work were widely recognized. While references to 'research' and 'evidence' were apparent across the range of participants, they were particularly prominent among the minority who were scientists themselves, knew scientists, or worked in a science-related profession. These participants often described how they themselves valued scientific evidence and would want to know that a therapy was 'proven' before they used it.

In contrast, other participants (mostly complementary therapy users) wanted health professionals to have a broader approach and give

greater value to a different type of evidence – patients' experiences. One mother described GPs' focus on scientific evidence as 'tunnel vision' and wished that they would have a broader outlook on topics outside of their knowledge base. Participants who attached less weight to scientific evidence pointed to the uncertainty of scientific knowledge and the complexity of the human body, suggesting that not everything can be explained by science. They perceived the medical profession's reliance on scientific evidence as a 'stumbling block' to their acceptance of complementary therapies.

Expectations of access to complementary therapy services via the NHS

Do patients and parents expect NHS access to complementary therapy services and if so, how?

Participants expressed a range of views about whether the NHS should provide access to complementary therapy services (see Box 7). The majority were in favour, both non-users and users, some of whom were positive in theory but did not expect such access in 'reality'. A minority of non-users argued strongly against. Key issues identified were patient choice, equity of access to services, costs, targeting and the role of scientific evidence.

Choice was a prominent concept among patients and parents, both non-users and users. They argued that patients need choice and alternatives to conventional drugs, a proportion of patients want to use complementary therapies and therefore the NHS should provide access. They did not expect NHS professionals to necessarily provide such services themselves, but hoped that GPs in particular could act as gatekeepers, referring interested patients to appropriate complementary therapy services.

Current inequalities in patients' capacity to access to complementary therapies were highlighted by several, with payment for private therapies identified as a barrier to those on low incomes. Participants who were from a deprived inner city area, and had accessed subsidized complementary therapies via their general practice, greatly valued the opportunities to use treatments that they would otherwise have been unable to afford. Thus many patients and parents were keen to see more equitable access to complementary therapies by incorporating them within the NHS.

Tempering the choice argument, the concept of targeting of complementary therapy provision was important for some participants. Targeting complementary therapy services for certain patient groups, rather than providing universal access, was suggested as a means of avoiding potential 'abuse' of the system by patients who do not really 'need' complementary therapies. The majority recognized that those therapies perceived to have 'proven effect' of benefit for most patients were most likely to be candidates for NHS provision, especially those that might help chronic conditions poorly served by conventional medicine. Chiropractic, osteopathy, Alexander Technique and acupuncture for back pain were cited as examples. In relation to asthma, breathing techniques such as the Buteyko Method were seen as having particular potential value for NHS provision, either by referral to Buteyko practitioners/teachers or by NHS staff (e.g. asthma nurses) trained in the techniques.

A minority of those interviewed (non-users) were very cautious about or strongly opposed to

NHS provision of complementary therapies, based on concerns about the perceived lack of scientific evidence for most therapies. Yet, even the most sceptical non-users saw promise in breathing therapies for asthma patients, as these were perceived to have a certain 'scientific' or 'logical' basis for treating asthma.

While most participants recognized the value placed on scientific evidence within the NHS, some suggested that this should not be the sole determinant of service planners' and providers' decisions about complementary therapies. Even those in favour of a strong scientific evidence base for complementary therapies acknowledged that much of conventional medicine is based on less than rigorous evidence.

Allocation of limited NHS resources: would complementary therapies be a resource drain or a long-term resource saver?

The extent to which complementary therapy provision would be a resource drain or resource saver for the NHS emerged as an important sub-theme (see Box 8). At one end of the spectrum, sceptical non-users argued that NHS resources are too stretched to provide complementary therapies, other needs and services are a higher priority, and therefore patients should pay for private complementary therapies if they wish to use them.

While in favour in principle of complementary therapies being provided on the NHS, some participants acknowledged that it was unlikely to happen at the current time because of resource constraints within the NHS, preventing the purchase of therapies or employment of appropriate staff to provide them. They recognized the complexities of weighing up which services can be provided within a limited NHS budget. If any complementary therapies were provided, they saw that this would have to be at the expense of another service or treatment and there would have to be selectivity regarding which therapies are offered. They perceived that these were likely to be those most closely aligned with a 'medical' approach.

Taking a longer-term perspective, some users argued that complementary therapies could

ultimately save the NHS money – certain therapies were seen as cheap as they rely on patient self-help, and if patients' complementary therapy use enabled reduction in their medication, this could mean a reduced drugs bill for the NHS. For example, they saw the potential for breathing therapies such as Buteyko to reduce the huge cost of asthma medication. Some users suggested that long-term cost savings could be made if the NHS allowed complementary therapies to play a role in preventative health measures. Examples given were the provision of regular chiropractic treatments to reduce conventional treatment costs for chronic back problems, and the increased use of nutritional therapists to improve patients' diets and prevent future health problems.

Motivators for greater NHS provision of complementary therapy services: patient empowerment and self-management

For several participants, a key advantage of complementary therapies was their potential to provide patients with tools to gain greater personal control over their condition, especially therapies with a strong self-help component (see Box 9). Such empowerment contrasted with the dependence that many patients with asthma felt upon their conventional medication. Participants often expressed unease about the medical profession's dependence on prescription drugs, and desired doctors to work more closely with practitioners who could provide non-drug alternatives and facilitate patients' self-help (e.g. counsellors, complementary therapists). One valuable aspect of working with complementary therapists was seen to be their potential to look at other deeper underlying causes of health problems, rather than just the presenting physical symptoms.

Some participants also argued that greater NHS access to complementary therapies could reduce health professionals' workload, as some chronic conditions could potentially be dealt with primarily by complementary practitioners (e.g. osteopaths for back problems) or increasingly self-managed by patients equipped with

enhanced self-help strategies, such as breathing techniques for asthma.

Barriers to greater access to complementary therapy services within the NHS: dominance of pharmaceuticals, limited medical sanction and a lack of political will

Participants recognized many barriers to a shift away from drug-based management of illness (see Box 10). They acknowledged that drugs are a 'quick' way of dealing with illness and are usually the first-line treatment, enabling a fast turnover of patients given the time constraints within general practice, for example. The time needed to explore alternatives within a consultation was seen as one barrier to doctors providing greater access to complementary therapies. The power of the pharmaceutical industry was seen to be a major block to the greater provision of non-drug alternatives within the NHS.

In addition, some perceived a lack of political will for greater NHS provision of complementary therapies and reluctance on the part of the medical profession to 'sanction' complementary therapies. The lack of political will was seen to be due not only to scepticism about the value of complementary therapies, but also to the perceived lengthy time-period required to evaluate the public health impact of introducing such services, which would exceed short political time-scales.

Discussion

Patients and parents in this study expressed thoughtful and insightful views about the complexities of integrating complementary therapy information and services within the NHS. They voiced a range of expectations regarding access to complementary therapy information and services via the NHS, and recognized key facilitators and barriers to greater access. Their hopes and expectations sat side-by-side with a realistic understanding of the constraints within the NHS.

Their expectations are both challenging and compassionate: challenging, for example,

because they want health professionals to have greater knowledge of complementary therapies; and compassionate because they are aware that detailed knowledge is unlikely for busy doctors facing increasing demands from evidence-based health care. While often expecting health professionals to be sceptical about complementary therapies – supporting the findings of previous research²² – there was recognition that new generations of doctors are increasingly ‘open’ towards complementary therapies, if not yet possessing detailed knowledge.

Previous research on asthma patients’ experiences of their conventional treatment has emphasized the need for doctors to have greater understanding of patients’ priorities and concerns, and for doctors and patients to share their respective knowledge within consultations.^{18,19} Our findings indicate that patients’ and parents’ expectations regarding mutual supportive communication with doctors extend beyond conventional treatments to complementary therapies. Even 20 years ago, consultations were described as ‘meetings between experts’.²³ Since then there have been many calls to recognize doctor–patient relationships as partnerships and to value the ‘expertise’ that patients hold.^{24,25} Previous research suggests that the traditional divide between ‘expert’ doctor and ‘lay’ patient is being eroded, with patients changing the dynamics of consultations by informing themselves about their condition (e.g. via the internet), challenging doctors’ knowledge and exploring how far their own knowledge will be incorporated into the consultation.^{26,27} This study illustrates some of these changing dynamics, in an area of knowledge that traditionally resides outside of the scope of mainstream medicine – knowledge of complementary therapies. Patients and parents using complementary therapies are likely to be informing themselves independently of their NHS care providers because of their perceptions of limited knowledge of complementary therapies among professionals, and thus could potentially be seen to hold the ‘expertise’ about this topic within their consultations. However, this study also indicates that the swing towards ‘expert patient’-

led consultations is far from wholesale, with several patients and parents desiring health professionals to be the informed ‘expert’ in order to advise them about complementary therapies, as well as the range of conventional treatment options. As a minimum, they expect health professionals to have greater knowledge of complementary therapies than their patients, perhaps challenging the concept of the ‘expert patient’ who knows more than their health professional.

Should anything be done to enhance health professionals’ knowledge of complementary therapies? There have been moves to increase awareness of and provide training in complementary therapies within certain professional bodies, health-care settings and educational establishments. For example, the ‘Tomorrow’s Doctors’ report by the UK General Medical Council states that doctors ‘must be aware that many patients are interested in and choose to use a range of alternative and complementary therapies. Graduates must be aware of the existence and range of such therapies, why some patients use them, and how these might affect other types of treatment that patients are receiving’.²⁸ A recent example is the development of the electronic database CAMEOL, that contains summaries of trial evidence for specific complementary therapies and conditions, with the aim of being a resource for health professionals.²⁹

Regarding NHS access to complementary therapy services, one possible motivator for greater provision highlighted by our participants was the potential to enhance patients’ self-help. The question could be asked, ‘Do complementary therapies offer the NHS any value through their potential role in enhancing patients’ self-management?’ There are increasing debates within the NHS about patients’ self-management of chronic illness.^{14,25,30} For asthma, these usually focus on written plans for symptom monitoring and medication use, provided by health professionals. This study suggests that complementary therapies may be an under-recognized aspect of patients’ own self-management strategies. Rather than seeing complementary therapies as a threat to an

under-resourced health service, they may perhaps open-up new ways of managing chronic illness that reduce patient dependency.

Our study participants were not naïve about the constraints on provision of complementary therapy services within a finite and already stretched NHS budget, and the challenges of accommodating competing needs and priorities. In many ways, their views mirror recent debates within the academic literature about the challenges of assessing the cost-effectiveness of complementary therapy provision within the NHS. For example, patients and parents' speculation about the potential for complementary therapies to save the NHS money through their role in preventative health, reflect recent (if contested) suggestions by Smallwood that certain complementary therapies could potentially bring long-term reduction in treatment costs if provided within the NHS.²

While realism about economic constraints was apparent, choice about NHS access to complementary therapies was the most prominent expectation, among non-users as well as complementary therapy users. This reflects a 'consumerist' approach to health care that prioritizes patients' rights to access preferred treatment options, mirroring the increasing policy emphasis on patient choice.^{4,31} Alongside their desire for choice, patients and parents were aware of the priority given to scientific evidence of effectiveness within the NHS, which might compete with their hopes for choice. They understood that even if patients are choosing to use complementary therapies, the predominant culture of evidence-based practice within the NHS, and the perceived lack of evidence for complementary therapies, is likely to prevent service planners and providers from accepting their value. Thus, complementary therapies illustrate an underlying tension between the patient-centred care and evidence-based medicine agendas within current health policy, noted by authors in relation to other health issues such as immunization.³² The question remains as to whether these two agendas are reconcilable – from the perspectives of our study participants this could begin to happen by broadening defi-

nitions of evidence, giving greater value to different kinds of evidence regarding 'effectiveness', namely patient experience.

This study is qualitative and the findings are not necessarily representative of the views of all patients and parents of children with asthma. In qualitative terms, we anticipate that the findings may be transferable to users and non-users of complementary therapies for asthma from similar settings in other parts of the UK. Participants were predominantly female, and those highly sceptical about complementary therapies were mostly male, mirroring previous research indicating that complementary therapy use is a predominantly (although not exclusively) female endeavour.³³ Some participants were drawn from a potentially atypical health-care setting in terms of the wider UK picture regarding NHS access to complementary therapies, i.e. an NHS homeopathic hospital. There is a possibility that they held particular views on NHS provision of complementary therapies. This could be explored further in future research specifically comparing views of users of NHS and private complementary therapies regarding NHS access, e.g. NHS and private homeopathy. However, to balance this, most of our participants came from 'ordinary' NHS settings (e.g. primary care), with no routine access to complementary therapies. Thus, we suggest our sample is not overly atypical due to our inclusion of patients and parents from a range of settings, with a spectrum of views and experiences.

Conclusion

Complementary therapies are rising up the agenda in health policy and practice. A growing number of patients with chronic conditions are using complementary therapies, including those with asthma. While previous research has examined asthma patients' needs and priorities regarding their conventional care, little attention has been given to their preferences and expectations regarding access to complementary therapies. This paper begins to address that gap by highlighting the range of expectations that patients and parents of children with asthma

hold regarding NHS access to complementary therapy information and services, and the rationales they give for their views. While service planners and providers may have reservations about the value about complementary therapies, it is important to take patients' preferences and expectations into account if policy discourses regarding patient-centred care and choice are to be realized in practice.

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