

Original article

The information needs and preferred roles in treatment decision-making of parents caring for infants with atopic dermatitis: a qualitative study

Background: Information needs and preferences in treatment decision-making of parents caring for infants with atopic dermatitis (AD) are unknown, despite emphasis on quality information-giving and involvement of health-care users in treatment decisions.

Objective: To explore information needs and decisional role-preferences of parents caring for infants with AD.

Methods: Qualitative study. Purposive sample: 31 parents caring for infants with AD. Tape-recorded focussed conversation-style interviews. Interview topic-guide literature-derived. Control Preferences Scale (5 sort-card vignettes 'very active' to 'very passive' role) adapted for use with parents; used to facilitate discussion. Thematic analysis of verbatim transcripts.

Results: Nine core information needs identified: AD-causation, role of diet, medication-use, medication-side-effects, exacerbating factors, new/alternative medication, nonpharmacological treatments, AD-prevention, AD and other atopic conditions. Parents desired verbal *and* written information. Many felt their baby's condition was not taken seriously, leading to delayed diagnosis and treatment. They had to be more active than they wished to obtain information/treatment. Parents preferred sharing decisions with their doctor.

Conclusions: Parents caring for infants with AD have clearly defined, unmet information needs, forcing them into more active roles in the treatment decision-making process than they desire. The study-findings may inform the development of written information specifically for these parents and improve partnership during consultations.

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Atopic dermatitis (AD) in childhood has increased steadily in the last four decades from a prevalence of 5% in the 1960s to a prevalence of 25% in the new millennium (1–3). However, data on parents' experiences when looking after a child, especially an infant with AD is scarce. Isolauri et al. reported that 90% of parents with an atopic infant find their care more troublesome than that of a healthy child (4). A significant negative impact on the daily life of an affected infant or young child as well as the whole family has been described (4–6). A National Eczema Society survey found that hospital doctors and general practitioners were failing to meet the needs and expectations of adult patients and parents of children with AD (7). The need to improve care for families looking after children with chronic conditions is becoming increasingly apparent (8, 9). Partnership, involvement

(e.g. in treatment decisions), information-giving and 'needs-led' care are promoted in current health care policy (10, 11). There have been a number of studies of these issues in the context of adult patients, however, parents' roles as health care users on behalf of their children are poorly understood (8, 12, 13). The aim of this study was to explore the information needs and preferred level of involvement in treatment decisions in parents caring for infants with AD. A qualitative approach was chosen to:

- Explore which symptoms parents find most troublesome for themselves and their baby who has AD.
- Obtain parents' views on the information they would most like to be provided with regarding their baby's AD.
- Identify how involved parents would like to be and how involved they feel they currently are in decisions about their baby's AD treatment.
- Obtain parents' views on factors which help and hinder them in taking part in treatment decisions.

Abbreviations: AD, atopic dermatitis; CPS, Control Preferences Scale.

Methods

During the recruitment of babies for an ongoing infant AD study parents' problems in caring for young infants with the condition became apparent. We decided that this was an area warranting formal exploration, using a qualitative approach in the first instance. Approval was given by the Local Research Ethics Committee and participants gave written consent.

The study took place in North-west England. Parents were recruited from the ongoing study (considered to be secondary care, paediatrician-led), a paediatric allergy clinic at the local teaching hospital and a local general medical practice. Parents were invited to participate if their baby was up to 12 months old and had doctor-diagnosed AD. Purposive sampling was employed to ensure a range of care-type and educational level. Focused conversation-style interviews were undertaken (14). The interview topic guide was derived from the literature, taking into account professional clinical experience, allowing for flexibility and exploration of new topics which emerged during the interviews. Data collection continued until no new themes were identified, i.e. category saturation was reached (14). All interviews were tape-recorded (with respondent's consent) and conducted by the same interviewer (RJ), who did not have a clinical background in paediatrics or dermatology.

The Control Preferences Scale (CPS; Table 1), consisting of five sort-card vignettes offering a choice from a very active to very passive role in treatment decision-making was used to focus discussion of decisional role preference. The vignettes, originally developed for use with adults, were modified for use with parents (15). Participants selected their most preferred, least preferred and perceived role in treatment decisions, using a 'pick one' approach. Rationales for these choices were then discussed, as were perceived facilitators of and barriers to participation.

At the end of the interview demographic data were collected. Interviews (each lasting 30–120 min) were transcribed verbatim and thematically analysed (14). All transcripts were read by at least two members of the research team. Themes were identified independently, then discussed and agreed by the team. There was a good level

of agreement regarding the main themes. The main themes were sent to participants at the end of the study for verification and were confirmed as accurate.

Results

Thirty-one mothers aged 21–40 years (mean 32 years) were interviewed (two fathers were present during the interview and contributed occasionally). They described themselves as White British ($n = 29$), Afro-Caribbean ($n = 1$) or Chinese ($n = 1$) and had a varying educational level (no formal qualifications $n = 2$, sub-degree $n = 8$, degree and above $n = 11$, professional qualification $n = 10$). Infants were aged 3–12 (mean 7.1 ± 2.4) months at the time of the interview, had varying disease severity and had been seen in primary care ($n = 5$), secondary care ($n = 6$) or an infant AD study ($n = 20$). The average age of onset of AD (mean 6.9 ± 4.4 weeks) was known for 20 of 31 infants which compares with the average onset found in the total 208 infants enrolled in the infant AD study (mean 6.8 ± 4.2 weeks; unpublished data, Gore C. et al). As formal severity scores were not available on all infants at the time of interview, medication use and attendance at accident and emergency (A&E) departments are given as surrogate markers for severity [based on the algorithm proposed by Eichenfield LF (16)]: 10 of 31 infants were classed as having mild AD (regular emollient use and intermittent mild topical steroid for flare control), 17 of 31 were classed as having moderately severe AD (emollients, regular mild topical steroids, $\pm$ topical and oral antibiotics), four of 31 were classed as having severe AD (emollients, regular mild topical steroids, antibiotics, hospital visits for severe flares). All parents, regardless of the severity of their child's AD had identifiable information needs and a discernable preference regarding their level of involvement in treatment decision-making.

Parental symptom perception

Parents observed the following symptoms in their babies: the skin was commonly noted to be red, dry, weeping, bleeding, crusting or altered in appearance ('cracked', 'lumpy', 'rough', 'sensitive'). The babies were reported to be itching, scratching, losing sleep and irritable. These symptoms were generally perceived as an indication of greater severity and parents reported finding them very distressing for the baby and themselves. Parents remarked that their babies' symptoms were often not taken seriously, and that diagnosis and treatment were often delayed, leading to more severe symptoms (Table 2).

Information needs

The nine core information needs with their main subcategories which emerged from the data are presented in

Table 1. Sort cards pertaining to current vs preferred role in the decision-making process [after Degner et al. (15)]

Card	Preferred role	Perceived role
A – active	I prefer to make the final decision about which treatment my baby will receive	I make the final decision about which treatment my baby will receive
B – active	I prefer to make the final decision about my baby's treatment after seriously considering my doctor's* opinion	I make the final decision about my baby's treatment after seriously considering my doctor's opinion
C – collaborative	I prefer that my doctor and I share responsibility for deciding which treatment is best for my baby	My doctor and I share responsibility for deciding which treatment is best for my baby
D – passive	I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion	My doctor makes the final decision about which treatment will be used, but seriously considers my opinion
E – passive	I prefer to leave all decisions regarding my baby's treatment to my doctor	I leave all decisions regarding my baby's treatment to my doctor

doctor being the general practitioner.

Table 3. All parents expressed the need for detailed information about the treatment of AD – i.e. medications available, their advantages and disadvantages. Many specified the need for a skin care plan, explaining exactly

Table 2. Issues around symptoms and diagnosis of atopic dermatitis ('eczema')

Symptoms described by parents

'...and starts getting really bad we have to tie his hands up again which we don't like doing at all, but there's not much else you can do otherwise he'll just tear himself apart.' '...he'll play and then he'll just be, just starting itching somewhere and that's, that's the most, most problem about it, his itching. But it's constant really, it doesn't...we've got to get him something long-sleeved so you are able to tie the hands'. MU031

'...the stress for myself when you put your baby to sleep and know what within five or ten minutes, in his sleep he would be scratching because he didn't know what to do, and he'd be bleeding,...and then because he wasn't sleeping then he wasn't feeding, so he wasn't really putting on much weight, erm, yeah, he just couldn't sleep...My boyfriend moved into the other bedroom and it was just, it was hard for everybody because it was literally every two hours he'd be up scratching, and it was the bleeding and having to change the sheets, change his outfits'. MU028

Issues around symptoms and diagnosis

[Health professionals say] 'No, no it's just dry skin', 'Oh, it's just eczema' – I don't think they realize how much children can suffer from it'...[He] hasn't really been diagnosed as eczema. I've told them he has eczema...I put him under their noses took 3 to 4 months before [eczema was] diagnosed' MU021, a mother whose older child had eczema too.

'...not just writing it off and saying 'It's just baby eczema'. MU009

'...it took three visits to the doctor before he was really given any treatment or explanation as to what might be happening', 'It could have been avoided really. You got in a mess, and that could have been avoided, had it been spotted beforehand' MU019

Table 3. Core information needs – main themes and their major sub-categories

Information required on	Details
Medication/treatment	Which conventional medications exist? How to use the treatment (application: how, where, dose, frequency, duration, how to stop) Clarify the word <i>sparingly</i> How to manage/maintain remission
Causation of AD	What causes and what is AD? Is it inherited/who can get it? Is it because of something I did?
Side effects of medication	Especially regarding topical steroids
New or different medication	Complementary/alternative therapy Alternatives (conventional) to topical steroids
Exacerbating factors	How to identify and avoid
Role of diet and dietary avoidance	In particular the role of dairy and breast-milk
Nonpharmacological measures	e.g. bathing, laundering clothes, choice of clothes, nail-care, measures to prevent scratching, distraction
Prevention of AD	
Natural history of AD and relationship with other conditions	

AD, atopic dermatitis.

which treatments to use, how to best use them and how to respond to improvements or flares. Most parents commented on the paucity of information about topical treatments and expressed the desire for more information about the role of food and environmental triggers and their avoidance.

Parents typically considered that information-giving was insufficient in quantity, lacked detail and was inconsistent; hence they had to actively seek more information to help them deal with their baby's condition (impacting on decisional role). Parents whose infants participated in the eczema-study generally felt better informed, but expressed the same information needs as parents who had attended either primary care or secondary care clinics.

How information should be presented

Almost all parents (28 of 31) desired some form of written information with many stressing the need for both verbal and written information (as a 'back-up'). Practical demonstrations on application of topical treatments would have been welcome (Table 4).

Decisional role preferences

The CPS was transferable to this group. Thirty of 31 parents completed the card-sort; one interview was terminated prematurely because of a fractious child. All parents had identifiable role preferences, overall preferring a collaborative role (Card C, Table 1); no parent wished to be 'very active' (Table 5). However, 22 of 30 parents felt they actually had an 'active' role, seven of these being 'very active' i.e. making treatment decisions independently of doctors. This was typically due to lack of information, inconsistent information or lack of time and/or interest from health professionals (Table 6). Facilitators of collaborative decision-making were reported as being consistent and detailed information, time for discussion and the belief that their infant's AD was being taken seriously (Table 6).

Discussion

This study has highlighted the considerable disruption and distress caused to babies and their families by AD. Despite its high prevalence and recognized adverse effect on babies' and families' daily lives (2, 5, 17, 18), many parents in this study felt that their baby's condition was not taken seriously, leading to delayed diagnosis and difficulty in receiving appropriate treatment. In light of this indifference, and faced with a highly visible condition and visible distress, parents found they had to be more active than they wished in order to obtain information about the condition and its treatment. These findings suggest the need for improved awareness amongst health

Table 4. Data extracts pertaining to information needs

Typical data extracts regarding what information is desired

'Erm, it'd be sort of good to know kind of what causes it really, and how to prevent it...Erm, just advice really on if there's any particular things I should avoid or, er, whether it's likely, like how long do you think it's likely to last for, whether she'd just grow out of it or...just general things'. MU024

'I just, I wanted to know really why was she getting it, was it diet orientated because it seemed to crop up at the same time as I was weaning her, and I thought she might have an allergy to milk or, you know that milk I was using, or perhaps some of the, the fabric conditioners or, you know, or the baby bath I was using, something like that, and I wanted to know also was she going to have to live with this for the rest of her life, you know'. MU030

Typical data extracts regarding suboptimal information giving

'...I was open to any information, I was quite desperate, because, I was, I mean, I was a first-time mum and (he) was quite, you know, he was red, he was sore, it was startlingly obvious he had a problem...and one doctor would say one thing and one doctor would say another. That wasn't reassuring. But then you're talking about things in young children that could possibly cause, you know, they've got skin thinning, and if it's particularly strong possible side effects in growth, you know, and then they say 'put it on sparingly' I mean, how long's a piece of string, what's sparingly, you know?

...my main issue was how to cure it, I wanted some information, and what had caused, what had I done wrong, that was in my mind, so, it was my fault, but what had I done wrong. The next question was how could I stop the next one getting it, and I didn't even bother asking the GP about.

I've met people at clinics, at baby clinics and things like that, and I've seen their skin, you know, covered in very severe eczema and I've been like, please, you need some cream on that, and they just don't get any information. I really don't think they get any information...The information, I don't think the information is there, and, considering that they're saying that there's more and more people, more children getting eczema, then the GPs need updating, or if they haven't got the time, they need to have more specialist nurses for example'. MU025

'I think I would like to have, erm, somebody give me all the information before I used it (treatment) to help me make the decision of whether I need to use it or not. I just felt that there wasn't enough information, they didn't know enough or, you know, they didn't, they didn't even seem that willing to sort of discuss it with me. It was almost like I was being a bit of pain, because I was making a bit of a deal of it'. MU029

'...because the first doctor, I think she said something to me along the lines of all my children looked like that, if it's any consolation all my children looked like that at that age, they all get rashes and things and it could be one of a million things. An when I think back now at that point in time it was probably infected as well, so it probably should have been dealt with...

What can cause it, erm, I mean thinking back now I probably found out on the internet things like the, keeping his bedding washed at 95°. Using emulsifying ointments, how to use hydrocortisone and how to use it, 'cos I only found that out form when (study doctor) and (research nurse) came round. Erm, what it is really, what eczema is. I just wish that the GP at the beginning had recognized it more quickly and explained more about the importance of emulsifying and, erm, proper use of the hydrocortisone really, that's the one thing that stands out'. MU019

Typical data extracts regarding how to best receive information

'I think verbally with written information, because you don't always take it in and sometimes afterwards you think oh, what was that exactly, or you know if you husband/partner/wife or whatever thinks, well hang on a minute, you know, 'I've always thought that it was very dangerous' like, I know that was certainly my husband's point of view. (...) Yes, how to use it, how often to use it, and when to stop using it, because obviously you don't want to use something full time, so I needed to know well when do I stop using this, when do I, when is it safe to stop using it and just use the moisturiser'. MU008

Somebody actually listening to me and thinking, taking me seriously

If you went to your GP and you could say, 'right, my child's got eczema' or 'is this eczema?' and they say 'yeah, it's eczema. Here's a pack, here's an information pack that's been put together by...and talks about itching and scratching'. MU025

Table 5. Parental role in decision-making (perceived vs preferred)

	Total	Preferred role				
		Fully Pref.	Fully active	Semiactive	Collaborative	Semi passive Fully passive
		30	0	12	15	2 1
Perceived role						
Total perceived	30					
Fully active	7		0*	3	3	0 1
Semi active	15		0	8	7	0 0
Collaborative	4		0	0	4	0 0
Mostly passive	2		0	1	0	1 0
Semi passive	2		0	0	1	1 0

*Bold numbers represent parents for whom perceived = preferred role (total n = 13).

professionals of the problems facing parents of infants with AD.

To our knowledge this study is the first which specifically addresses information needs and decisional role preferences in parents of infants with AD. The study shows that these parents have clearly identifiable information needs, which often go unmet. These parents' information needs share some commonalities with those of adult patients with various conditions, common areas being information about treatment/medication (types, use, new/alternative treatments, side effects), aetiology and progression/prognosis, and lifestyle issues (19–21). Some information needs were specific to this group, e.g. mothering issues (nonpharmacological measures), dietary avoidance, the role of breastfeeding and prevention for future babies. The nine core information needs identified in this study may be helpful in focussing time-constrained consultations towards patients' priorities and in targeting information-giving most appropriately.

Coulter et al. (22) highlight the importance of service-user involvement and taking account of users' needs throughout the process of developing health information. The nine core areas identified in this study may thus be useful in the development of information leaflets for parents of infants with AD. Adult patients view appropriate information as a key element in making informed decisions (8, 13, 19, 21, 23). This was also expressed by parents of children suffering from epilepsy, especially regarding medication decisions (23). Most parents in our study preferred a collaborative role in treatment decision-making. This is consistent with the partnership approach currently advocated (8, 13, 24). Very few parents preferred to defer treatment decision-making entirely or largely to health professionals (Card D or E). This may reflect the fact that parents of an infant-patient have to act as the advocate for the child, hence prefer (or feel compelled) to have some involvement in treatment decisions. Only 13 of 31 parents in our study achieved their most preferred role in treatment decision-making, with most being more active than they wished to be. This

Table 6. Data extracts pertaining to decisional role-preferences

Active Role Preference – Typical Rationale

Mother: 'Again, because I probably don't feel that the doctor would, speaking at the, not now, but at the time it was very bad, I don't think the doctor felt, I didn't feel the doctor was taking it as seriously as I felt it was at the time'

RJ: So that then led you on to being more active?

Mother: 'Yeah, a bit more pro-active and finding out for myself what was going on'. (MU019, perceived role A–B, most preferred role B)

'Well I have to say I make the decisions, my husband and I make the decisions, but principally I make the decisions. Yeah. He either supports, questions, agrees or disagrees...I feel I am happy taking the last stance in that, yes, I am happy to go along that road, but I need other people to give me all the information so I can make informed choices, therefore I can make the decision, yeah'.

MU008 (perceived role B, most preferred role B)

Collaborative Role Preference – Typical Rationale

Mother: '...if I have a doctor that's explaining things to me and it's not just a case of there's the cream, go and do that, but explaining and sort of going into depth about, you know, the different possible causes of eczema or whatever the problem is, then I, I think that would be more of a two-way partnership working together really'.

RJ: 'What is preventing you achieving the shared...?'

Mother: 'I think consistency really across the board, erm, like you've got the hospital in [locality] that are, that are sort of giving this advice on this detailed skin programme, yet other professionals in the health care system don't seem to be aware of the at particular programme, or that they're giving you different advice...you'd have the consistency there and you wouldn't have the conflicting advice going on, and, erm I think people would just feel more confident really. I certainly would as a parent'.

RJ: 'What made the advice so successful?'

Mother: 'Erm, the fact that you had sort of one-to-one, erm discussions, erm, I didn't feel, erm, I felt that my opinion was valid, erm, and I felt that I had the opportunity to express my concerns'.

MU027 (perceived role A, most preferred role C)

Mother: 'You know, and I'm not undermining that knowledge at all, you know, he is a very knowledgeable person, of course he is, and I'm not saying that I'm more knowledgeable, because he's got a knowledge that I can't, I can't have and I won't ever have, so, so in that, in that respect it would be good to share it because I have a knowledge of my child, I have a knowledge, he doesn't know my child, I know my child, erm, and he doesn't have a knowledge of my wishes, my lifestyle, his lifestyle, so he's got a knowledge and I've got a knowledge and I think it would be best if those knowledges culminated and we, you know, we achieved a joint knowledge

RJ: What is forcing you into this (active) role?

Mother: Because he doesn't, he's not asked me my opinion. And when I gave, or, I didn't mean asking about dairy products, I didn't even give him my opinion, it was, it was, you know, just suggesting something that I'd obviously heard about, and that was, it wasn't even considered, not for a second, so, and it should be I think'.

MU020 (perceived role B, most preferred role C)

'All the advice I've received has been very erm, they're, they're kind of very understanding, they're not telling me what to do...So it's sort of I'm in control but giving me the tools and then...'

'I prefer that my doctor and I share responsibility, not that I don't want to make the decision, because I prefer to, you know, its just that I I'd like to have, you probably don't need to know this but, erm, share the responsibility, cos I know its my responsibility, its not the doctors responsibility. But I like to have a share that what I'm doing is OK with the doctor, because I just don't want to make a decision, that he might think, you know I might not have all the information'.

MU006 perceived role C, most preferred role C)

Passive role adopted – typical rationale

'Well I think really the doctor sort of makes the decision at the minute. (...) I, well, leave it, I leave it to the doctor really. (...) It's hard to say 'cos the doctor basically just tells you what creams and thing, like, that you should use, so you go, OK and you do it'.

MU024 (perceived E, most preferred C)

finding contrasts strongly with previous studies of adult patients with such conditions as asthma, renal disease, dental problems and cancer (15, 20, 21, 25, 26), in which patients typically report being less involved in treatment decisions than they prefer. This makes our finding unusual, in that parents perceived often themselves as very active or semi-active and generally would have preferred a less active role. Parents' high level of involvement in treatment decisions was ascribed to a lack of consistent and detailed information, coupled with their child's condition being underestimated and under-treated. This resulted in parents independently making decisions about starting, stopping or adjusting treatment, or indeed engaging in interventions (pharmacological or otherwise) on a 'trial and error' basis. This could clearly have adverse implications for the well-being of infants with AD and suggests the need for more support for these parents.

Limitations of the study

The study has a qualitative design which gives it high internal validity, but limited generalizability. This could be addressed by using the findings as a basis for further quantitative studies to test if the themes identified can be confirmed in other samples. Recruitment was difficult from primary and hospital secondary care and some parents had a child enrolled in an ongoing infant AD study. This may have influenced our findings. In addition, information needs and role preferences may change over time and further, longitudinal work would be needed to explore this. The sample was largely White British (reflecting the local population's composition). Information needs and decisional-role preferences of minority ethnic groups may differ from our sample's. Only mothers were interviewed. This was appropriate as mothers are typically the primary carers in the first year of their baby's life, and hence the main person involved in health-care utilization. However, this may have influenced the findings.

Conclusions

Parents as health-care users have not been well studied although they represent a growing group of health-service users. Health professionals under-estimate the level of distress caused by infant AD and information-giving regarding this condition is suboptimal. This appears to force parents into an unwelcome high level of independent decision-making about their babies' treatment. The study's findings could contribute to improved understanding of these parents needs and could facilitate enhanced information-giving.

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