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Title: The parental experience of prophylactic antibiotics (PEPPA)

Corresponding author:

Dr Simon Hardman, Room 9, Academic Unit Child Health, Sheffield Children's Hospital, Damer Street, S10 2TH. Email: simonhardman@doctors.net.uk

Co-authors:

Dr Fiona Shackley. Sheffield Children's Hospital NHS Foundation Trust, Immunology, Allergy and Infectious Diseases, Sheffield, UK

Professor Alison Condliffe. The University of Sheffield, Infection, Immunity and Cardiovascular Disease, Sheffield, UK

Dr Kelechi Ugonna. Sheffield Children's Hospital NHS Foundation Trust, Paediatric Respiratory Medicine, Sheffield, UK

Dr Andrew Lee. The University of Sheffield School of Health and Related Research, Public Health, Sheffield, UK

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Abstract

Background and objectives

Long-term prophylactic antibiotics are often used to prevent bacterial infections. However, supporting evidence for this is not always robust. Including parents in decisions relating to medication is key to medicines optimisation. Parental concern regarding medication is a major determinant of poor adherence. This study explores parental experiences of having a child prescribed prophylactic antibiotics and how that affects their antibiotic use behaviour.

Methods

We conducted a prospective single centre exploratory qualitative study at Sheffield Children's Hospital. Through 15 interviews, involving 18 participants, we explored parental 'lived experiences' and attitudes towards azithromycin prophylaxis prescribed for various respiratory conditions. Thematic analysis was conducted.

Results

The overriding factor influencing parental decisions about the uptake of antibiotic prophylaxis, is wanting their child to be well now. The main concern voiced by parents is that of antibiotic resistance given their children are high users of antibiotics. This is however seen as a problem for the future, not the present. Preparing families adequately helps prevent practical difficulties relating to medication. Facilitating "normalisation" of prophylaxis through daily routines and minimising disruption to the family environment may reduce parental anxiety, promote adherence and result in easing of potential restrictions to the child's daily activities.

Conclusion

Grounded in our deeper understanding, we propose a behavioural model that describes phases parents go through whilst having a child on prophylactic antibiotics. Time invested in holistically addressing the parental experience and having an awareness of potential issues parents face, may facilitate medication adherence, reduce anxieties and improve doctor-parent relationships.

The parental experience of prophylactic antibiotics (PEPPA)

Background

Long-term prophylactic antibiotics are often used to prevent serious bacterial infections and their sequelae in susceptible populations. Evidence-based guidelines for antibiotic prophylaxis exist for conditions such as HIV [1]. However, in other conditions the supporting evidence is less robust [3]. Azithromycin prophylaxis is often used in children with recurrent respiratory tract infections due to its antibiotic and anti-inflammatory effects. It is recommended for conditions such as bronchiectasis [4]. The benefits of antibiotic prophylaxis need to be weighed against potential risks of antibiotic resistance and medication side-effects.

Including parents and children in decisions relating to medicines is key to medication adherence [6]. Indeed, parental concerns regarding medication contribute to poor adherence, which is a significant problem in chronic paediatric illnesses [7, 8]. Parental knowledge and beliefs are essential considerations when changes in patterns of antibiotic prescribing are required [9].

Few studies have investigated parental perceptions of antibiotic prophylaxis. Parents may see antibiotic prophylaxis as beneficial [10, 11], but this may not necessarily result in good adherence [11]. Parental concerns about antibiotic resistance were perceived to be a community problem rather than an issue affecting their children [10]. This study seeks to understand the parental experience of having a child prescribed prophylactic antibiotics and how that affects their antibiotic use behaviour.

Methods

Participants and procedure

We conducted a prospective, single-centre, exploratory qualitative study at Sheffield Children's Hospital (SCH) with parents or guardians whose children attended the paediatric respiratory and immunology outpatient clinics. All participants gave written informed consent. Travel expenses were covered but no other incentive to participate was offered.

Parents of children aged 2-10 years who had been taking oral azithromycin prophylaxis for at least 3-months to prevent lower respiratory tract infections, were invited to participate.

Recruitment took place between September 2018 and April 2019 using a purposive sampling method to capture a breadth of views based on the ages of parent and child, parental education and severity of the child's condition (Figure 1). Theoretical saturation was anticipated to occur between 12 and 20 interviews [12].

Interviews

Face-to-face interviews were conducted by SH, at SCH or the family home, depending on parental convenience. Semi-structured interviews were conducted using an interview questionnaire based on topics of interest to the research question and themes previously identified in the literature relating to parents' perceptions of acute antibiotics (Appendix 1).

Interviews focused on parents' "lived experiences" of having a child who had been prescribed prophylactic azithromycin. Parents were encouraged to fully describe their thoughts and

feelings regarding prophylactic antibiotic use. An iterative approach was taken building on emerging themes from previous interviews.

Interviews were recorded using an encrypted digital voice recorder.

Analysis

All interviews were transcribed verbatim and standard thematic analysis conducted [13].

Transcripts were coded by SH and reviewed independently by a second researcher (AL). A framework of subthemes was developed and iteratively adapted following each interview. We focused on finding recurrent, unusual, collective and opposing subthemes, in order to understand how parents experienced the events they described, why they had made certain decisions and factors influencing their behaviour.

Three themes and associated subthemes were identified and agreed on through a continuous process of refinement and discussion between researchers. Background medical and social information was used to contextualise the meanings of comments.

Ethical approval was granted by North West - Haydock Research Ethics Committee (Reference 18/NW/0579)

Results

18 parents took part in the study through 15 interviews. The participants' characteristics are summarised in table 1. Six interviews were conducted at SCH and nine in the participant's home. The average interview time was 45 minutes (30-70 minutes range). From these interviews, three main themes emerged as described below (See table 2).

1. Decision making regarding prophylaxis

Parents took on both active and passive roles in medical consultations when making decisions regarding the use of antibiotic prophylaxis. Some parents had strong feelings of being experts of their children and wanted to more actively engage with consultants. Parents who described taking a more passive role reported feeling less informed. Barriers to engagement identified by these parents included chaotic consultation rooms, time pressures, social norms of politeness, not wanting to be made to feel like a "drama queen" and seeing the doctor as a higher authority.

"I go into clinic and they (doctors) are sat at the computer typing. It's rare they give you eye contact... They tell me the plan... I don't' want to bother them asking questions. It isn't till I come home I think, is it doing him any good (prophylaxis)?" (Parent 9)

These barriers led to unvoiced concerns that in turn meant parents sought increased support from health care professionals. Interestingly, three parents described a transition from passive

to active involvement once prophylactic antibiotics were discussed. Reasons behind this included perceived significant risks of antibiotic prophylaxis, a desire to improve their knowledge given the increase in severity of the situation and frustration at feeling uninformed.

“We now constantly ask questions. Not to be difficult but we want to know why... You hear a lot in the press about antibiotics so we had lots of questions.” (Parent 1)

All parents hoped antibiotic prophylaxis would reduce the number of respiratory tract infections, improve their child’s health and restore normality to their lives. Fear of a common cold progressing to a hospital admission and significant clinical deterioration was a recurrent concern. Parents talked about how their health beliefs of antibiotics sometimes conflicted with a decision to start long-term antibiotics. Such health beliefs included aversions to taking antibiotics as they had not needed them in childhood and fears about what antibiotics do to the body.

“I was brought up with homeopathy and it always worked... I hate antibiotics but they have worked... I was grateful, but uncomfortable with him having them.” (Parent 4)

The majority considered antibiotic resistance when deciding on antibiotic prophylaxis for their child. This was often described as “the body becoming immune to antibiotics”. Parents perceived their children to be at “high risk” for acquiring resistant organisms due to high

antibiotic exposure. This however was not seen as an imminent threat for their children rather as a problem for when they were older. Medication side effects were less well appreciated.

Most parents reported antibiotic prophylaxis was the only option left having exhausted all others. Other contributing factors included pressures of poor school attendance and competing demands from siblings and employers, due to multiple hospital admissions. The desire for their child to be well and have a better quality of life at that moment in time was overwhelmingly the most significant factor when deciding whether to try prophylactic antibiotics.

“Here and now I just wanted him to be as well as he can be.” (Parent 13)

2. The context of prophylaxis within the family and their environment

Parents described various ways in which they normalised their lives incorporating their child’s antibiotic prophylaxis. Establishing a routine was the main way of creating a sense of normality. This was often achieved using visual cues and electronic devices as reminders. A number of barriers were cited such as school holidays, when the established routine was interrupted and ensuring timely collection of prescriptions. Some parents admitted it was easy to forget to give the antibiotics.

Parents often have to reconstitute the antibiotic powder at home. Whilst this negates the need for weekly pharmacy visits to collect pre-made suspension, many parents were not expecting to have to do this and found it somewhat daunting.

“I was given this bag of medicines and it freaked me out... What if I forget one day? Could he get an infection because I've given him his antibiotics in the afternoon and not the morning?”

(Parent 5)

They also found it difficult to get repeat prescriptions in a timely fashion which impacted on adherence. Two parents said that significant prescription difficulties made them want to stop prophylaxis.

“I had nothing but hassle with this antibiotic. Just the simplest thing from getting it from the chemist... Even now, I didn't have no medicine for him on Monday.” (Parent 9)

Many were concerned about the amount and cost of wasted antibiotics and were not aware of appropriate disposal methods. Some reported flushing surplus antibiotics down the toilet or sink.

Most parents felt prophylaxis was beneficial in reducing infections, hospital admissions, or improved school attendance. Some reported they previously isolated their child from social

situations that had potential for infection. They viewed antibiotic prophylaxis as a protective measure which enabled their child to take part in more activities.

“If he wasn't on antibiotics, he wouldn't set foot in that place (soft play). I'd be too scared of him picking something up... While ever he's on these antibiotics, I've got that little peace of mind they're protecting him” (Parent 5)

A few parents described prophylaxis as a reminder that their child was susceptible and needed their activities restricted.

3. Response to acute illness whilst on prophylaxis

Despite taking prophylactic azithromycin, most children had breakthrough respiratory illnesses.

There was often an initial emotive response when parents heard their child starting to cough.

This evoked fears of progression to a hospital admission. Combined with feelings of helplessness and futility of self-help measures, parents often felt driven to take action.

“Even if he coughs twice in his sleep, you go, here we go again...I always expect the worse. A lot of the time it is viral and I know antibiotics won't help but you feel like you are doing something.” (Parent 1)

Parents found it difficult to decide on the threshold for consulting a healthcare professional during acute illnesses. As well as looking for clinical cues, they also reported social norms and

practicalities as barriers to consulting. These included, “not wanting to waste the doctor’s time” or being seen as a “paranoid mother” and difficulties making GP appointments.

The perceived severity of their child’s illness and susceptibility did not always correspond to that of the healthcare professional or underlying diagnosis. Parents of two children with bronchiectasis had higher thresholds for seeking medical attention and isolated their children less, despite having a more severe underlying diagnosis.

“Because of our not wanting her to be on antibiotics too much, coupled with her not getting high temperatures, we haven’t been getting extra antibiotics that much.” (Parent 11)

Parents’ understanding of science, relating to antibiotics and infections, plays a role in determining their expectations for antibiotic prescribing. All parents knew antibiotics should not be used for common colds. Despite some knowing viruses caused the common cold, the term “infection” was often misinterpreted as being severe and requiring antibiotics. Confusion arose when they were told their child had a virus but were given antibiotics for the “viral infection”. This reinforced the severity of the situation and started a cycle of expectations for future antibiotic courses.

“There’s quite a few bugs like viruses and stuff that can be beaten by the human body... Obviously when it’s an infection it needs treating by antibiotics.” (Parent 2)

Discussion

The overriding factor influencing parental decisions about the uptake of antibiotic prophylaxis, is wanting their child to be well now. The main concern voiced by most parents is that of antibiotic resistance, but this is seen as a problem for the future, not the present.

Based on our key themes, we propose a possible behavioural model describing phases parents' cycle through once their child is prescribed antibiotic prophylaxis. (figure 2).

The first phase is the decision making process to commence prophylaxis. Following this, a period of stability ensues as a new normality is created. The outcome of which varies with regards to antibiotic adherence and restrictions to childhood activities. Most families cycle through a disruptive stage of acute illness and reflect upon their experience. This leads back to reassessing the decision for antibiotic prophylaxis.

An awareness of this cycle may help clinicians prepare families for prophylaxis, pre-empt potential difficulties and focus on areas to improve the family's experience.

Parents have the responsibility of making medical decisions on behalf of their children. Those parents actively participating in decisions have feelings of security and control over the situation and are more convinced the treatment prescribed is correct [17]. In comparison, those passively taking part are reported to have post-consultation decisional conflict and feel powerless and insecure [17]. Parents may not always want to be actively involved in decisions.

Their desire to be involved may change with time, knowledge, the gravity of the decision and their emotional response [18].

From our study, clinicians should be mindful of passive parents with unvoiced concerns when making decision regarding prophylaxis. Breaking down potential barriers that dissuade parents' participation may help a transition to more active involvement. This includes acknowledging parents as experts in their own right, irrespective of health literacy, focusing eye contact on parents rather than computer screens and addressing social norms.

Previous reports suggest parents perceiving their children as low antibiotic users do not see antibiotic resistance as an issue for their children [16]. However, parents in our cohort see their children as high users of antibiotics, who are at risk of resistance (albeit in the future) and weighed this factor when making decisions about prophylaxis. This was not reported in the only previous study looking at perceptions of parents on an oncology unit [10] and is a novel observation.

It is important to prepare parents for prophylaxis. Discussing the practical aspects of medication and ways to normalise this may facilitate adherence, acceptance and reduce anxiety. Clinicians should be aware that paradoxically, parental anxiety may increase with prophylaxis promoting a sense of susceptibility to infections resulting in childhood activities being further restricted.

Discussing thresholds for seeking medical assessment during acute illnesses enables parents to feel they are seeking assessment at appropriate times, alleviates anxieties and through good

communication with general practitioners, raises awareness of suggested management plans. This in turn may break a cycle of expectations for future antibiotics.

Our study has limitations. The cohort of parents interviewed does not fully represent the diversity of families seen at SCH. Only three male parents and one non-white British family were interviewed. The parents interviewed may be a self-selecting group, choosing to participate in order to voice concerns or opinions. Parents who did not participate may potentially have other diverse experiences. The interviewer was a paediatric registrar whose medical outlook may have biased the questions asked and interpretation of the parents' comments. Finally, further research is necessary to explore the ethnic and cultural dimensions influencing parents' experiences and to confirm the proposed model which may not be generalisable to other indications of antibiotic prophylaxis.

Conclusion

It is not sufficient for clinicians to prescribe prophylactic antibiotics with the expectation that parents will adhere. This "current" approach does not take into account the complex interplay between health, psychology and behaviour. We need to address the parental experience holistically when prescribing long-term antibiotic prophylaxis by preparing families and breaking down barriers that prevent their active involvement in consultations. Time and effort invested in this we believe, would facilitate antibiotic adherence, reduce anxieties and improve relationships between parents and medical professionals.

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Contribution Statement

FS conceived the idea. All authors contributed to the study design. SH conducted the interviews. AL and SH conducted the initial analysis and developed the framework of themes. AC, FS and KU contributed to the final analysis. SH drafted the manuscript. All authors provided critical feedback and helped shape the manuscript.

“What is already known on this topic”

- 1) Parental knowledge and beliefs have been identified as essential factors to consider when changes in antibiotic prescribing are required.
- 2) Active parent involvement in decision making promotes feelings of security that the correct medication has been prescribed.
- 3) Parents feel that prophylactic antibiotic use is beneficial and are less concerned that antibiotic resistance may directly affect their children.

“What this study adds”

- 1) Parents feel antibiotic prophylaxis is beneficial but they are concerned about future antibiotic resistance affecting their children and running out of treatment options.
- 2) Improving preparation for antibiotic prophylaxis may help address issues of adherence, antibiotic resistance and reduce parental anxieties.
- 3) A behavioural model reflecting different phases parents go through with regards to antibiotic prophylaxis is proposed that could be used to enhance parental experience.

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Table 1: Participant characteristics

Demographics	N = Frequency Total interviews = 15 Total participants = 18
Participant interviewed	Mother = 14 Father = 2 Grandmother = 1 Grandfather = 1
Age of interviewee (years)	21-30 = 2 31-40 = 7 41-50 = 7 51-60 = 1 61-70 = 1
Highest degree	None = 2 GCSE = 2 NVQ = 7 Higher degree = 7
Employment status	Employed = 10
Ethnicity	White British = 16 Arab (Libyan) = 2
Mean Age of child (years)	4 (2 – 6)
Mean duration on prophylaxis (months)	11 (3-31)
Child's diagnosis	Protracted bacterial bronchitis = 9 Bronchiectasis = 3 Hyper IgM = 1 Congenital tracheal stenosis – post operative = 1 Muscular dystrophy = 1
Number of acute antibiotics over past 12 months	Median = 2 courses (range 0-3)

Table 2: Themes identified in the analysis

Main Theme	Subtheme	Codes	Referenced quotes in Table 3
Decision making regarding prophylaxis	Determinants of active involvement	Self-belief	1.1 P10, P6
		Health literacy	1.3 P1
		Impact on parent	1.1 P8
	Passive Barriers	Social norms	1.2 P9, P2 1.3 P6
		Environmental	1.2 P1
	Influencing factors	Perceptions of prophylaxis	1.6 P6, P14
		Health beliefs	1.4 P3, P4, P9 1.5 P12, P2
		Impact on quality of life	1.4 P8
		Understanding of science	1.5 P10
	Balancing risk	Benefits	1.6 P3
		Present vs future	1.5 P7
		Concerns	1.6 P13
The context of prophylaxis within the family and their environment	Normality	Establishing a routine	2.1 P2
		Barriers	2.1 P6
	Practicalities of medication	Preparedness	2.1 P5 2.2 P14, P8
		Administering issues	
		Waste and disposal	2.2 P15
	Adherence	Obstacles and difficulties	2.2 P9, P10
		Initiatives	
		Impact on quality of life	2.3 P2, P3, P4, P5
	Response to acute illness whilst on prophylaxis	Emotive reasoning	Immediate response
Previous experiences			3.1 P8
Assessment		Threshold for consultation	3.2 P11
		Importance of specific symptoms	
		Driving pressures to take action	3.1 P1, P12
Management		Misconceptions of terminology and concepts	3.3 P2
		Expectations	
		Understanding of antibiotics	3.3 P5

Legend.

Table 2 shows the framework of subthemes that developed from codes applied to the interview transcripts. A consensus of three main themes was then agreed upon. This was through discussions amongst the researchers with regards to interpretation of the findings consideration of the surrounding literature and ensuring the story line of the participants was conveyed. Supportive quotations from the interviews are referenced within table 2. These can be found in Table 3 (P=parent)

Table 3 Anonymised quotations (Parental consent specifically obtained)

Theme identification number	Quotations
1.1	“We all help to decide. I mean if we weren't doing our job as parents, keeping an eye on him, we wouldn't know he's got that cold and things like that.” (Parent 10)
	“They (doctors) are qualified. They think they know best. But they don't. They don't go through the nights of the child not sleeping because they can't breathe, they do not know... they might know on a medical concept.” (Parent 8)
	“They will ask, do you have any questions and how we feel about his medication. It does feel like a 2-way discussion. It's not that we are being passive.” (Parent 6)
1.2	“...the doctor tells me the plan is and as a parent I just go along and think he's the doctor, he knows best... I think me asking questions, I'm holding that doctor up, I don't want to bother him. It isn't till I come home I think, is it doing him any good (prophylaxis)? Is it harming him?” (Parent 9)
	“You can't always concentrate. Your toddler is sticking his hands in the orange bin with the gross stuff or dragging a car up the wall when you are trying to listen to really important information. It's ever so difficult. (Parent 1)
	“I go into clinic and they (doctors) are sat at the computer typing away or writing. It is very rare they even give you eye contact. And you think they are under so much pressure and you are just another body. I feel I'm just another body, with another poorly child.” (Parent 9)
	“I don't want to seem like a paranoid mum. I feel she has taken a turn for the worst when she is coughing and being sick. Believe me I'm not a drama queen” (Parent 2)

1.3	<p>"We're in such a position now that we constantly ask questions. Not to be difficult but we want to know why. We had big questions about long term antibiotic use. You hear a lot in the press about the use of antibiotics and so we had a lot of questions regarding that. It was us asking rather than people proactively telling us anything." (Parent 1)</p>
	<p>"I think people perceived doctors being that higher authority that sometimes can't be questioned. That is not how it is in society these days. Doctors are saying you are the expert on your illness." (Parent 6)</p>
1.4	<p>"I was brought up with natural medicines and homeopathy and it always worked. I hate antibiotics because I was brought up to hate them. But they have worked so I was grateful, but very uncomfortable with him having to be on them." (Parent 4)</p>
	<p>"Again I've mixed feelings. Because I think, is it natural to be on an antibiotic for all that long term?" (Parent 9)</p>
	<p>"I was always very anti antibiotics. If I could get away without having them, I would. I mean your body can stop most things. (Parent 3)</p>
	<p>"We won't go on holiday because we are fearful that it is going to be another hospital admission and we don't want to be in a strange place in a strange hospital. (Parent 8)</p>
1.5	<p>"You just don't want him to get something really bad when he is older and nothing (antibiotics) works." (Parent 7)</p>
	<p>"Well it would be a problem for him wouldn't it when he is older." (Parent 14)</p>
	<p>"I mean I were brought up with you got antibiotics for pretty much anything. But I know nowadays they don't like it. As you get older and you really do need them, if you have them too often you are eventually immune to it." (Parent 12)</p>
	<p>"If you take antibiotics, your body can grow immune to it." (Parent 10)</p>
	<p>"It's just a bit of scaremongering. It goes whichever way it wants to go, media in my opinion... They play it down a bit like antibiotics won't cure your cold and stuff. But for us, we're not abusing antibiotics. It's quite clearly she's dependent upon them. We have to go with the specialists." (Parent 2)</p>
1.6	<p>"I was a bit worried about how long is it going to be before they (prophylaxis) stop working. Because I know your body builds up a resistance towards them... I just thought about him being well now. I mean in years to come there might be more antibiotics available. Here and now I just wanted him to be as well as he can be. Like he were only at school 50% of the time. So he were behind on school work. I thought that it were the right thing to do to start him on the antibiotics." (Parent 13)</p>
	<p>"Well, I could have said no I don't want (prophylaxis) but there wasn't like... well if you don't want to do that we'll do this instead. So it was kind of like you can do this or you can't do this, but there was no like this is another option. (parent 14)</p>
	<p>"It (prophylaxis) felt as if it was something that was done almost as a last resort." (Parent 6)</p>
	<p>"Erm I just hated seeing her so ill all the time. I just wanted them to do something, I didn't care at the time what. I was happy for her to try them (prophylaxis) at that point. And I never thought I'd say that as I'm not an antibiotic fan. I never used to be but I am now." (Parent 3)</p>

2.1	<p>"I was given this bag of medicines and it was you need to give it to him Monday Wednesday Friday and it freaked me out to be honest... I were terrified of forgetting. What if I forget just one day? He's going to get ill. If I don't give it to him on time, what if I give them to him late, will that make any difference to him? Could he get an infection because I've given him his antibiotics in the afternoon and not the morning?" (Parent 5)</p>
	<p>"...it's easy to forget it. I mean you go a week and actually no he's not had it... Yeah we do find that he will start to be more unwell. Like we notice he just gets a bit more wheeze especially at night. Have we done it, have you done it? No, ahh that might be why." (Parent 6)</p>
	<p>"Remembering what day you are on when you are doing Monday, Wednesday, Friday, (can be difficult). Whereas if it's part of your daily routine, yeah we just get up, brush our teeth, have our medicine, have our breakfast and mark it on the calendar which we all share. (Parent 2)</p>
2.2	<p>"The consultant explained it very well, what it was for, what they hoped it would do, and he would stop it. It was literally I had no idea it was a powder and I had to make it so that was a bit of a surprise." (Parent 14)</p>
	<p>I had nothing but hassle with this antibiotic. Just the simplest thing from getting it from the chemist because at the start they wouldn't give me dry powder to make it up myself. So I was like battling to and fro trying to get this antibiotic and even now, I didn't have no medicine for him on the. So every month I've had to phone up the doctors and say, I've no medicine left for Monday. (Parent 9)</p>
	<p>"On a personal side of things it were like, thank God we don't have to do that now (administer prophylaxis)... It's a case of that little bit of relief now." (Parent 10)</p>
	<p>"The new antibiotics only last 5 days. You have to discard whatever is left.... I'm wasting antibiotics every week, which... That is NHS money. (Interviewer: What do you do with the antibiotics?) Well I just have to flush it away. We don't know how to dispose of it really." (Parent 15)</p>
	<p>They don't provide you with enough information when they give them (prophylaxis) you. They just say here, have some antibiotics. So I don't know much about the antibiotics to be fair. (Parent 8)</p>
2.3	<p>"Like I said with the ball pools and things like that. If he wasn't on those antibiotics, he wouldn't set foot in the place. I'd be too scared of him picking something up. While ever he's on these antibiotics, I've got that little peace of mind that they are protecting him. If he came off them I'd think that would stop and the only place he'd go would be the garden.." (Parent 5)</p>
	<p>"She now does swimming lessons whereas I couldn't let her do that before because I'd be worried in case she picked more bugs up." (Parent 3)</p>
	<p>"I throw her in at everything. When we are outside, she can do mucky play. I don't treat her any differently (being on prophylaxis)" (Parent 2)</p>
	<p>We haven't been swimming but yeah in terms of mixing with people, I feel more comfortable that I know we have got that cover. But if someone has got a cough, don't cough on him but he has got the antibiotics. Yeah so I guess it gives you some kind of reassurance that he's not completely on his own. (Parent 4)</p>
3.1	<p>"Even if he just does 2 coughs in his sleep, you go, here we go again. You know and I try and put it into perspective because I think well... We always get through it... So</p>

	<p>yeah when he starts with a cough. I always expect the worse. We'll end up in hospital he'll go onto oxygen." (Parent 1)</p> <p>"Back to chest infections and in and out of hospital. It's a destruction of her life that she doesn't need. A common cold can quite easily turn into a severe chest infection. It is just stress. Stress for her, stress for me and progression from normal common colds to chest infections. It is just so drastic." (Parent 8)</p> <p>"But a lot of the time it is viral and I know that antibiotics won't help but you feel like you are doing something. And I know that... but as a parent you want to be doing something." (Parent 1)</p> <p>"(giving acute courses of antibiotics) you feel like you are doing something. I mean when kids get poorly you feel pretty helpless. Cough syrups don't work. You can't give them decongestants. So you can pretty much just give them paracetamol and hope it works." (Parent 12)</p>
3.2	<p>"Initially we were told; when she has a temperature it might be that she has a worse infection so get her checked out. She gets temperatures less times than not. So that is not a very good gauge for us. Then we were told if her cough is lasting for a couple of weeks, go and get it checked out. And then we were told actually 2 weeks is too long to be waiting. So because of our not wanting her to be on antibiotics too much, coupled with her not getting high temperatures, we haven't been going and getting extra antibiotics that much. So, I think that is why we have been told, we need to lower our threshold... So I guess the more it happens, the more I'm getting to know when she might need to have some extra help and when not." (Parent 11)</p> <p>"It's a bit stressful because it is difficult to get a GP appointment and I know it sounds awful but to fit it in. To try and fit it in, phoning up at 08:00 in the morning...I don't necessarily feel like I'm doing a good job at managing it." (Parent 11)</p>
3.3	<p>"You can get other bacterial infections like hand foot and mouth, that was going round school and I kept him at home...They ask people not to take antibiotics for a cold because they don't work. There's nothing you can do its gonna run its course unless it does change and you get an infection then you can have some antibiotics." (Parent 5)</p> <p>"There's quite a few bugs out there like viruses and stuff that can be beaten by the human body but obviously when it's an infection it needs treating by antibiotics." (Parent 2)</p>

Legend

Quotations in this table have been taken directly from the interview transcripts. They have been selected to support the themes developed in the final analysis as reported in table 2 and described in detail within the results section.

