Parental experience of prophylactic antibiotics

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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 regarding 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 while 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.

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. However, in other conditions the supporting evidence is less robust. 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. The benefits of antibiotic prophylaxis need to be weighed against potential risks of antibiotic resistance and medication side effects.

What is already known on this topic?

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

What this study adds?

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

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 infection, immunity and allergy team in the first 2 years of age. Parents were selected through convenience sampling and were approached in the ward or in the children’s respite area. We conducted 15 interviews, involving 18 participants, using a semi-structured interview guide. Interviews were audio-recorded and transcribed verbatim.

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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.10

Interviews
Face-to-face interviews were conducted by SJH, 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 (online supplemental 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.11 Transcripts were coded by SJH 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.

RESULTS
Eighteen 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 min (30–70 min range). From these interviews, three main themes emerged as described below (see table 2 with further quotes in online supplemental appendix 2).

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
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 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)

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 among the researchers with regard 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 and can be found in online supplemental appendix 2 (=parent).

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 on. This was through discussions among the researchers with regard 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 and can be found in online supplemental appendix 2 (=parent).

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 have to do this and found it somewhat daunting. (Parent 12)

These barriers led to unvoiced concerns that in turn meant parents sought increased support from healthcare 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.

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.

**Response to acute illness while 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 its viral and I know antibiotics won’t help but you feel like you’re 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 general practitioner 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 restricted 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 parents’ comments. Finally, further research is necessary to explore the ethnic and cultural
Figure 2  A behavioural model illustrating the parental experience of having a child prescribed prophylactic antibiotics. We propose this behavioural model to explain the cycle of phases parents experience when their child is prescribed prophylactic antibiotics to prevent recurrent respiratory tract infections or progression of bronchiectasis. The first phase begins with parental acceptance of their decision to commence antibiotic prophylaxis after weighing up the associated risks and benefits. The context of taking prophylaxis on the family and their environment must then be considered. A desire to normalise prophylaxis ensues in order to address social norms of not wanting their child to stand out and to make life as easy as possible. This is achieved by establishing routine and minimising environmental disruptions. Parents rationalise their decision if exacerbation frequency reduces. Previous concerns may be suppressed and a sense of security develops. Restrictions placed on their child’s activities may be lifted. Adherence may be promoted as prophylaxis is seen as vital or complacency may develop. Episodes of acute illness inevitably occur. These induce fear that their child will deteriorate and prophylaxis has failed. An objective response follows drawing on previous experiences to assess and manage the situation. Barriers need to be overcome if assessment by a healthcare professional is felt necessary. Determining the threshold for assessment is difficult for parents but potential drivers are their perceived severity of symptoms or fear of deterioration/end organ damage. After the acute illness, parents reflect on their parenting response and outcome of the assessment depending on whether treatment was given or not. This may influence their assessment and expectations of future illnesses as well as reflecting on the efficacy of the antibiotic prophylaxis. Parents then re-evaluate their decisions.

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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