Parent's information seeking in acute childhood illness: what helps and what hinders decision making?

Sarah J. Neill PhD PGC Res Deg Sup PGDE MSc BSc(Hons) RGN RSCN RNT,* Caroline H.D. Jones PhD MA MSc BSc(Hons),¶ Monica Lakhanpaul MB BS MRCP (UK) DM FRCPCH,‡ Damian T. Roland BMedSci (Hons) BM BS MRCPCH,§ Matthew J. Thompson DPhil MPH DTMH BSc MB ChB MRCGP† and On behalf of the ASK SNIFF research team

*Associate Professor in Children's Nursing, School of Health, University of Northampton, Park Campus, Northampton, †Senior Researcher, ¶Senior Clinical Scientist, Department of Primary Care Health Sciences, University of Oxford, Radcliffe Observatory Quarter, Oxford, ‡Professor of Integrated Community Child Health, General and Adolescent Paediatrics Unit, UCL Institute of Child Health, London and §Consultant in Paediatric Emergency Medicine, Paediatric Emergency Medicine Leicester Academic Group, Cardiovascular Sciences, University of Leicester, Leicester, UK

Abstract

Context Acute illness is a universal experience in early childhood. Parents find it difficult to determine whether or not their child requires medical care and seek information to inform their decision making. Little is known about parents' information seeking behaviour and what helps or hinders their decision making.

Objective This study aimed to explore parents' use of information resources during decision making in acute childhood illness at home.

Design/Method This exploratory qualitative study used focus groups and interviews to collect data from parents of children under 5 years of age.

Setting and participants Twenty-seven parents were recruited in the East Midlands, UK, in South Asian and Gypsy/Travelling communities, a Children's Centre and a private sector day nursery.

Findings Parents' pre-consultation information seeking was dominated by the internet, albeit with limited success. Parents liked easy to access, professionally validated and simple messages with access to more detailed information. Some parents always sought information through personal contact, whilst others did so when independent information seeking failed. When consulting a healthcare professional, parents liked to be given information to refer to later, although the information received varied. Importantly, neither hard copy nor the internet was accessible for parents with low levels of literacy.

Discussion and conclusions Although there is a wealth of information parents can access independently, our findings indicate a need for easy access to clearly signposted, professionally validated resources and available in a range of formats provided through different delivery systems. One size does not fit all.

Introduction

Acute childhood illness is a universal experience and is particularly common in the first 5 years of life. Families manage between 59 and 99% of acute illness episodes at home[1–4] with just the tip of the iceberg presenting to health care. Research suggests that this is, in part, because parents feel they are expected to contain minor illness at home.[5] Uncertainty and anxiety surround parents' decisions to seek medical help[6–8] leading to a desire for more information to inform their decision making.[8–10] Parents find it increasingly difficult to determine whether a child requires urgent care, as reflected in the 42% increase in children's emergency department attendances in the last decade[11] and the increase in use of primary care and out-of-hours services.[12] Many hospital attendances could potentially have been managed in the community.[11,13–15]

There is limited evidence about parents' information seeking prior to consultation other than the use of the internet.[16–20] It is important to know what helps and what hinders parents' decision making currently, for example what information sources help parents to make decisions and what are not useful and why. This evidence could be used to improve resources, thereby enabling parents to make appropriate choices about home care and/or consultation.

We aimed to explore parents' use of information resources during decision making in acute childhood illness at home. This study reports the different sources of information parents described accessing during acute childhood illness and why, both before and during consultations with healthcare professionals (HCPs), across a range of social groups.

This study is part of the Acutely Sick Kids – Safety Netting Interventions for Families (ASK SNIFF) research programme, whose overall aim is to co-develop effective information resources for parents on acute childhood illness.

Methods

A qualitative method was used due to its strengths in exploratory research, particularly for topics such as this, where there is limited prior research. A modified grounded theory approach was chosen for its explanatory power.[21–23] We used the principles of grounded theory as a systematic framework for data collection and thematic analysis rather than to develop a core category. Sampling was designed to capture maximum variation in the socio-economic characteristics of parents through recruiting in communities with differing social, economic and ethnic profiles in natural settings. Recruitment was facilitated by the local primary care research network, the Comprehensive Local Research Network and community centre leaders.

Ethical considerations

Approval to conduct the study was obtained from the East Midlands – Nottingham 2 NHS Research Ethics Committee (REC reference 12/EM/0076), the research and development officers of each local Trust and the managers of the day nursery and community centres. Written informed consent was obtained from participants, all of whom were English speaking. The participant information sheet and consent form were read aloud for individuals with limited literacy.

Data collection

Data were collected primarily through focus groups, due to the ability to generate discussion and deeper insight, with supplementary individual interviews for parents who were unable to attend focus groups. Five focus groups with between two and eight parents and three individual interviews were conducted between May and December 2012 with parents of at least one child under 5 years of age. They took place in the East Midlands, UK, including South Asian and Gypsy/Travelling communities, a SureStart Children's Centre (community centre supporting families with children up to the age of 5 years) and a private sector day nursery. Two researchers (a children's nurse lecturer and a social scientist) conducted the focus

groups (together) and interviews (separately), which lasted between one and two hours and were held in community centres, the day nursery and a parents' home. An initial open question was used followed by prompts as necessary (See Box 1). Focus groups/interviews

---

Box 1 Focus group/interview topic guide

Starter question:

- When your children are ill at home where do you look for information to help you decide what to do?

Prompts:

- How easy was it to find information?
- What problems do you try and find information about?
- In what ways, if any, did it help you to decide what to do?
- What else, if anything, were you hoping to find out?

---

were audio recorded, transcribed verbatim then anonymized. In addition, parents completed questionnaires detailing demographic information.

Data analysis

Data were analysed using constant comparative analysis. NVivo 10, qualitative data analysis software, from QSR International (qsrinternational.com) was used to manage and code data. Substantive coding generated the initial descriptive codes from which emerging themes were identified. These themes then informed theoretical sampling and, therefore, future data collection within succeeding focus groups/interviews in the form of questions used to confirm/refute or clarify themes. For example, following identification of internet forum use in the first focus group, we asked for parents' views on, and use of, internet forums in the following focus groups. The resultant data enabled us to confirm their use for emotional support rather than information on childhood illness. Constant comparative analysis was employed

to compare each data set with preceding coded data, enabling substantive codes to be refined and theoretical coding to be developed as the relationships between codes were explored. Coding was developed by SN (a children's nurse lecturer) and CJ (a non-clinical researcher), and discussed with the wider research team (including GP, paediatric and emergency medicine clinicians, and parents from the ASK SNIFF parent panel). The parent panel also provided a measure of the trustworthiness of the analysis as they reviewed coded data and its interpretations by the research team.

Participants

A total of 27 parents (24 mothers and three fathers) participated in the study, including 10 White British, 11 South Asian, and six parents from Gypsy/Travelling communities (English Gypsy/Roma or Irish Traveller). Six parents were under 30 years of age, sixteen were 30–39 and five were aged 40–49 years. Most families had one or two children, within a range of 1–9 children. Three parents were single or divorced, the remainder were married. Nine parents were working full time, six part-time, three were either unemployed or studying and nine classified themselves as looking after children at home. Access to the internet at home was universal for all White British families, most South Asian families and the exception for Gypsy/Travelling families. Maximum level of qualification reported by parents varied widely between groups with White British parents generally being educated to a higher level (See Table 1 below). Participants were offered anonymized copies of the transcript of their focus group/interview for comment, although none were received.

Findings

Common themes were identified across each of the different settings and ethnic groups. The main themes and subthemes emerging from the data are presented in Table 2 and discussed

Table 1 Maximum educational levels reported by parents

Maximum educational levels reported	University	College	School	NVQ Level 2	No qualifications	Missing data sets
Gypsy/Travelling families (*n* = 6)	0	2	0	0	3	1
South Asian families (*n* = 11)	6	0	2	1	1	1
White British families (*n* = 10)	9	0	0	1	0	0
Totals	15	2	2	2	4	2

Table 2 Emergent themes and subthemes

Themes	Subthemes
Sources of information	Independent information seeking: delivery systems
	Personal contact: lay sources and health service use
Factors influencing information received	Healthcare professionals' parental status
	Healthcare professionals' time
	Perception of parents' competence (inc. parental status & parity)
	Social distance between parents and healthcare professionals
Factors influencing information access and use	Father's working patterns
	Literacy
	Timing of information delivery
	Advertising on websites

below. Tables are used to display quotes illustrating each subtheme.

The following abbreviations are used with data extracts: Focus Group = FG; Interview = Int.

Sources of information

Independent information seeking: delivery systems

Parents reported using three different information delivery systems: digital, hard copy and broadcast media.

The internet was reported by most parents to be their default information source. However, this was not their first port of call when a child was acutely ill as it is too time-consuming and too difficult to use a keyboard with a distressed child.

Parents reported being more likely to search the internet for information once they had a diagnosis, when they are 'fairly certain it is

nothing' (SureStart FG Mother) but just want to check, when they want support from their virtual social network, and when they want to check self-diagnosis in order to try to avoid the inconvenience of, and risk of criticism from, an appointment with a doctor. Searching to find out 'what things could be' (Gypsy/Travelling Family FG Mother) or for symptoms was not perceived to produce useful results.

Parents reported usually starting searches from Google, even when intending to use NHS Direct (UK health service advice on-line (also available as telephone helpline). Open internet searching generated conflicting information adding to uncertainty about the nature and severity of their child's illness and increasing anxiety for some parents. This uncertainty was associated with a feeling of being bombarded with information, although internet searching was also reported by some parents to decrease anxiety. One mother stated that it enables her to identify illnesses which are 'not really gonna be that important' (SureStart FG Mother).

Internet forums appeared to supplement physical social networks, particularly in the White British community where participants described their friends being geographically dispersed. They provide access to social support during antisocial hours: 'you don't want to have to disturb your friend at 3 o'clock in the morning' (day nursery FG Mother). Although parents said they might not trust information from these sources, they felt that, 'It's reassuring to know that other people are going through the same kind of things...' (day nursery FG Mother).

Two parents reported using Smartphone apps for information. One mother liked the ease of use and implied that because apps limit

the information presented on any one screen this helps to prevent information overload. However, this can still increase anxiety as 'it makes you wonder more actually' (South Asian Community FG Mother) about what might be wrong. The other mother had tried to use the NHS Direct app but stopped before getting the information she was looking for as there were too many questions. This suggests that parents expect Smartphones to provide faster access to simplified information than the web.

Importantly, digital media were not an effective medium for those with limited literacy, including participants in the Gypsy/Travelling and South Asian communities. These parents referred to others in their local communities for advice, who were able to read or write in English or in their first language.

Television was a valued source of information for parents either within programmes or within health promotion campaign advertisements (e.g. Meningitis 'glass test'), particularly for parents with low levels of literacy in English.

Parents reported using various hard copy presentations of information including books, maternity information packs (known as the Bounty pack), the personal child health record (the red book), flash cards, leaflets and posters. The majority of these sources were provided by health services, as preparatory information on the birth of a child, or following consultation. Posters in the hospital setting provided key messages on what to 'look out for' (South Asian Community FG Mother) – such as fever and rashes. Most parents were unaware of childhood illness information contained within sources of general information on child health such as the Birth to Five book. Small 'flash' cards on childhood illnesses, specifically meningitis, were referred to by one mother, and another reported being given a credit card sized concertinaed booklet on childhood illness. See Table 3 for further illustrative data extracts.

Table 3 Sources of information theme: independent information seeking subtheme – illustrative quotes

Internet searching	Day Nursery FG Mother
	If you've got a sick child at home and they're maunging at you, you haven't got the time to go on the internet, print off a checklist to take to the doctor with you because you've got a child hanging off your leg going, "Mummy I feel poorly, Mummy I want this, Mommy I want that," or you know, screaming or, I don't think it's that practical that often you don't have the chance to go on the internet.
	South Asian FG Mother
	I have accessed the Internet, but I find it makes me more scared.
	Community Interview Mother
	Uhm, I always find that there's quite a lot of information on there and you get bombarded with lots of paragraphs which you don't really want… On the NHS Direct… you have to go through the whole lot of the information before you get to what you want.
Internet forums	Sure Start FG Mother
	I suppose I use forums more because actually my friends are scattered throughout the country
Smart phone apps	Day nursery Interview Mother
	It's when you've got a screaming child that's ill, you've got another two running around snapping at your feet and you're desperately trying to decide, work out what on earth to do with the sick child, anything that you can get an app for that you can literally press a button…
Hard copy	Day nursery FG Mother
	It would be handy to have it [printed information]*, I prefer that anyway, I prefer to have, look down and then it's always there to look back on, you know.*
	Community Interview Mother
	When S was younger… they used to give you cards with symptoms on like meningitis
	Day nursery FG Mother
	I did have… they gave me a little credit card-sized book …and it pulled out, it was sort of concertina… about childhood illnesses

Personal contact: Lay sources and health service use

Personal contact with others was the preferred option for some parents as it was only through such contacts that they felt reassured. Others turned to personal contact when the use of information accessed independently did not meet their needs.

Lay sources. All of the communities referred to the use of family experts, usually grandmothers, as a source of information with the exception of the two White British mothers interviewed on a one to one basis. One explanation is that data from focus groups with White British parents, reporting the use of such family experts, may simply be a form of 'group speak', presenting socially acceptable accounts. In the South Asian group parents described asking their mothers (who were living with them) for advice, explaining that in South Asian culture families respect elders for their experience. Gypsy/Travelling families have extensive family networks within their local community – within which parents reported seeking advice from those with the most experience of caring for children, and volunteering advice to younger less experienced mothers suggesting that advice may not always be sought but given unbidden. Parents in each group referred to the need to examine advice received for its currency and relevance.

In the day nursery, advice seeking from nursery nurses was reported and parents commented that talking to the nursery manager gave them confidence to seek advice from a GP. Parents also reported asking family members who were HCPs for advice before seeking help from primary care.

Health service use as source of information. Parents reported using the NHS Direct telephone service, primary care, emergency services and their local pharmacy. Phoning NHS Direct was quicker than searching the internet. Parents reported liking 24-hour access, particularly at night, when they want to be able to access someone for advice 'just to make sure' (Gypsy/Travelling Family Int Mother). Some liked the extensive questioning and found it reassuring; others found the questioning could 'make you more distressed' (South Asian Community FG Mother) that the questions were irrelevant or simply that NHS Direct 'just tell you to go to your GP anyway, so that's not necessarily the most helpful' (SureStart FG Mother). Parents were also irritated at having to retell their story during contact with NHS Direct. Sometimes the wait for call back was too long, increasing parents' anxiety.

Some parents explained that it was only through face to face assessment that they could feel reassured that they were not missing something more serious. Most would rather see a GP for their child than any other member of the primary healthcare team, although they also said they would see a nurse if this meant their child would be seen sooner. They wanted their child to be *seen* so that they could be visually and physically assessed.

Parents explained that they wanted: a diagnosis; reassurance that it is not serious; information on what to do, when to worry; help to understand information from the internet; and, in some cases, to confirm their own diagnosis. Information received from GPs was reported to be written and/or verbal with most just receiving verbal information, often only when prompted by parents themselves. Those given printed information viewed it positively, as they did referrals to specific websites (in the few cases where GPs referred them to a website); however, there were few reports of parents referring to this information during the child's next episode of acute illness.

Parents reported problems with the out-of-hours service (OOHS) including irrelevant questions (like NHS Direct), difficulties keeping their phone line free for call back, increased anxiety whilst waiting for call back and problems with prescription medication not being made available where there were no chemists open locally. Dissatisfaction with the OOHS could, parents said, lead to them taking their child to A&E.

Although health visitor (HV) services were mentioned by parents in all of the data sets,

parents did not seek childhood illness information from HVs. Parents talked about the reduced contact they now have with HVs and implied that this had reduced their relationship with them. Some parents contacted the HV to check whether or not they needed to take their child to the doctor. There were no reports of HVs providing written information.

Parents reported limited use of pharmacies as sources of information or as first contact for child health issues, although, if they were not happy with advice from the GP, some then tried the pharmacy. One problem reported by parents was finding a local pharmacist that was open out of hours for advice or for prescription medicines. Parents also commented that they would avoid pharmacists as sources of information due to their inability to prescribe for children under 5 years of age. See Table 4 for further illustrative data extracts.

Factors influencing information received

Parents perceived that there were four factors which influenced the information they were given by HCPs. Firstly, perceived demands on HCP time created pressure; parents felt that time pressures limited the information doctors could provide, describing their consequent use of the internet to supplement it. Secondly, some parents felt that HCPs' attitudes towards them, and the information they provided, were influenced by whether or not HCPs themselves were parents. For example, parents reported feeling that becoming a parent made HCPs more sympathetic. Thirdly, parents perceived that HCPs altered their response according to their assessment of the parents' competence. For example, they described reduced information provision to parents of more than one child (an assumption of knowledge). Fourthly, parents reported that the social distance between parents and HCPs limited information they felt able to give and, consequently, the information HCPs provided in response. Some parents felt intimidated by and/or feared criticism from HCPs indicating that parents position themselves as subservient to the HCP,

illustrating perceptions of doctors' superior location within the social hierarchy. The unequal power distribution in such relationships can result in communication dominated by those with the most power such as HCPs, consequently inhibiting parents' ability to communicate their concerns. See Table 5 for further illustrative data extracts. Social factors identified in the data as influencing parents' help seeking behaviours will be reported separately.

Factors influencing information access and information use

Fathers described particular problems accessing hard copy or verbal information, due to their traditional roles in British society as they continue to be the parent most likely to be in full-time employment. They struggled to access health information about their children as many information delivery systems are designed around daytime attendance, including consultations with GPs, child health clinics and community education events. Fathers explained that they were reluctant to access these at weekends because this would eat into time when they could be with their children.

Low levels of literacy also created problems for both fathers and mothers, as described above. Stress, created by the child's illness, was also described as reducing parents' ability to understand instructions or to recall information.

Parents talked about the timing of information provision. Before the birth of their child, the mother's main focus was on the developing baby and the birth, rather than the possibility of childhood illness thereafter. Information provided immediately after the birth was valued at the time but later not used. When parents did consult a doctor with their child, some were given information during the consultation, usually verbally and often only in response to questions from the parents themselves.

When searching the internet, parents described how they judged the quality of the information on a particular website. One mother stated that she tries 'to only use UK

Table 4 Sources of information theme: Personal contact: lay sources and health service use subtheme – illustrative quotes

Lay sources	Family experts	Day nursery FG Interviewer: *C, what about you, where do you go first for information when your kids are sick?* Mother 2: *My mum, because I still live at home with my daughter as well so my mum is a big one that I go to... especially when she's still so young, you can think, you know the silliest little thing like a cold or something, 'Oh is she OK, do I need to take her to the doctors?' but that's when my mum will come in and she'll be like, "No, she's fine, you know, all the things you went through when you were little," and that helps.*
	Extended community	Gypsy/Travelling Family FG Mother C: *I mostly ask people that has loads of children... I wouldn't ask someone young like myself, I'd ask someone elder than me.* Gypsy/Travelling Family FG Mother B: *We are a very close community and asking for advice for children, yeah. It does work with us. I found it works with me and if I can help someone else and look at the child, I will. I think he needs to be brought to hospital then I'll say take them in.*
	Family HCPs	Community Interview Mother: *We have quite a few adults in the know and I will definitely….my sister's* [a nurse] *my first port of call.*
Health service sources	NHS Direct	Day nursery FG Mother: *they ask you questions that to you feel completely irrelevant, they probably are relevant but it's just really long winded and to try and get an answer and then they say, "Oh just go on hold and I'll put you through to a nurse," so I've just told you everything and I've got to tell somebody else again.*
	General Practitioner	South Asian FG Father: *I think even though we've got lots of ways of accessing the information I think we still trust the doctor, compared to our family, friends, community, colleagues...* Day nursery FG Mother: *I think there's, nothing can take you away from the physically seeing somebody and seeing your child.* Nursery Nurse FG Mother 1: *I've never come out with anything like; I've come out with information in my head...* Day nursery Interview Mother: *...again it was me instigating it, I think I could have walked out the door quite easily without the doctor saying anything was like, "Right, what happens next in terms of worst case scenario, what should I be looking out for? And if not, you know, how long should I be expecting this to go on for, when should they be getting better?" etc. etc.*
	Out-of-hours service	Day nursery FG Mother: *And then that's really hard because you're just like, "I'm sorry but I've got to get off the phone," and then the doctor's rang and then he's moaning to you then that he's tried to ring you and the phone was engaged, that's happened to me.*
	Health Visitor	Day nursery FG Mother 1: *Go to your health visit and get your child weighed so what's changed since I had my first one to my second one is the amount of time you do see your health visitor or get your baby weighed, so I don't even think that, I think that's changed.* Mother 2: *I think it's their, I just, I feel they can be a bit judgemental...*
	Pharmacy	Day nursery FG Mother: *I don't tend to use pharmacists that much for information for my children... Purely because they don't tend to be able to give me anything,... if they're under five they go, "Oh I'm sorry, we can't sell it to you," so I don't tend to use the pharmacist for information that much.*

Table 5 Factors influencing information received theme – illustrative quotes for each subtheme

HCP's parental status	Day nursery FG Mother
	A health professional that's got kids because they understand a bit more... I think they're possibly, possibly a bit more sympathetic...
HCP's time	South Asian FG Mother:
	They give you no time as well, 10 minutes or 5 minute consultation.
	Nursery Nurse FG
	Mother 2: *You feel the pressure to like right; I've got to get out.*
	Mother 1: *There is pressure to get out quickly, I think, so I think you do forget what the doctor has said.*
	Interviewer: *Does it maybe also have an influence on what you're able to ask?*
	Mother 1: *Definitely, yeah, I think so.*
Perception of parent's competence	South Asian FG Father:
	The information obviously with the second or third one was a little bit more vaguer than the first one.
	All three children are different. None of them are the same, and they've all had different symptoms...
Social distance between parents and HCPs	South Asian FG Father:
	And I have seen some doctor, GP, reception staff, not the most friendliest of people, you know, you've come across. So, there is that feeling I think amongst some people...I'm gonna get told off!
	Gypsy/Travelling Family FG Mother:
	You feel intimidated by doctors more because the doctors, you think that they know everything but you know that what they're saying is not what you've got but you feel like you can't argue the point with them.

sites' (day nursery Int Mother), whilst others avoid websites containing adverts. See Table 6 for further illustrative data extracts.

Discussion

What helps parents' decision making

Parents' pre-consultation independent information seeking was dominated by the internet in this UK study and elsewhere[18,20,24] as this is, for most (but not all), easy to access as most parents have internet access at home. During the acute event of a child's illness, however, internet searching proved difficult. Only 8.5% of parents in Goldman and Macpherson's[17] study searched the internet immediately prior to attending a paediatric emergency department. Hard copy sources of information continue to be used by some parents. However, embedding

Table 6 Factors influencing information access and information use theme – illustrative quotes

Fathers' working patterns	South Asian FG Father:
	If the resources are stretched Monday to Friday then, you know as fathers and parents we do want to, you know, access some help weekends and evenings and spread it through maybe you know like, speaking to the employer that there is something I need to go to so that... maybe the employers need to be a part of giving you the hour off or...
Literacy	Gypsy/Travelling Family FG
	Mother A: *A lot of us can't read or write.*
	Mother B: *They wouldn't know to walk over to a stand and pick up a leaflet 'cause they wouldn't know what's said on the leaflet.*
	Mother A: *It shows you on television, [what to] watch out for*
	Mother B: *So I think they do pick up a lot, travellers do rely on the adverts and that a lot more.*
Timing of information delivery	South Asian FG Mother: *It has to be after [the birth].*Interviewer*Beforehand you're thinking about the birth?*
	South Asian FG Mother: *Because like you said, pregnancy,... you know 39 weeks he's forming eyebrows, or she is and there's so much information about the birth.*
Advertising on websites	Day nursery Interview Mother:
	if it's got any advertising on it at all I come off it because I think they're going to try to plug me something that they're trying to sell, I'm like, no.

childhood illness information in general child health information sources does not appear to be effective as such information seems to be lost in amongst that on general child development. Although information provided at the time of the birth of the first child is valued, its active use is reported to cease after a short time. Learning theory tells us that information needs to be relevant to the learner[25–27] and for parents, this means delivering information when it is relevant to them.

Parents liked simple messages such as those presented in media campaigns or on flash cards and some looked for similarly short succinct messages on smart phone apps, although the latter was less common in our study than Mosa et al.'s[28] review would suggest. Parents also wanted to be able to access more detailed information as necessary. The most important qualities of information sources preferred by parents were ease of access and professional validation of the content of the information.

Some parents always sought information through personal contact, whilst others did so when independent information seeking failed to meet their needs. When choosing who to approach for advice, parents often chose first to access lay experts in their social networks or family HCPs. These sources were then sometimes used to legitimate the need for consultation with a HCP. These findings reflect those of Neill et al.[29] that parents seek advice from those sources which present the least risk of criticism, thus preserving their moral identity as good parents able to cope with minor illness and respond appropriately to serious illness, also avoiding any loss of face or discredit in Goffman's[30,31] terms. Carl Rogers'[27] principles of student-centred learning identified the importance of low threat to self for learning to take place. Therefore, it seems that parents' strategies both protect their social identify and optimise potential for learning.

When parents do consult a HCP, they like to be given printed information or a website to refer to later, as it is often difficult for them to assimilate all of the information given verbally when consulting with a distressed or active child. Reinforcement of learning, by revisiting information, is thought to be important to the assimilation of new knowledge.[32]

What hinders parents' decision making

Although parents' independent information seeking is dominated by the use of the internet, this is fraught with problems. In the absence of clearly signposted internet resources for childhood illness, searching the internet risks information overload, inconsistent information and, as a consequence, increased anxiety about their child's health. Internet searching is also time-consuming and can be difficult to do whilst caring for a sick child. Virtual social networks, whilst important for reassurance, are not reported to be a key source of information, but they do enable the sharing of controlled information about experiences without loss of 'face' (in Goffman's[31] terms), as relationships are often entirely virtual.

Importantly, neither hard copy nor the internet is accessible for parents with low levels of literacy. These groups appear, currently, to have very limited access to information other than through verbal conversations with others or from broadcast media. Yet, these are the families who are likely to have lower educational levels[33] and have greater need for learning resources about childhood illness.

Parents also experienced difficulties in their use of health services as sources of information. Parents felt that the information received was influenced by a range of HCP-related factors: time pressure, assumptions made about parents' knowledge and the social hierarchy of doctors relative to parents. The latter creates anxiety for parents during consultations as a consequence of feeling their moral worth as a parent is being judged.[29] In this study, parents reported that this anxiety could both reduce their ability to give information about their child's illness and to later recall information given, potentially resulting in reduced, or inappropriate, information for the parents concerned.

Limitations and strengths

The majority of data were collected retrospectively through focus groups which may have generated socially acceptable answers. These answers also reflect parents' recall of events; however, it is this memory which will influence their future behaviour. The addition of interview data enabled the identification of possible 'group speak' through comparing data from focus groups with that from interviews. There was only one difference identified which has been discussed above. This suggests that parents did feel able to share their experiences in focus groups regarding other areas of the data.

A maximum variation sample was recruited to limit bias, which included mothers and fathers in a wide age range, in different socio-economic groups, with a range of family sizes and differing access to information. Constant comparative analysis enabled us to identify differences between groups such as the differing patterns of information access associated with levels of literacy or cultural family norms. We did not observe notable differences in opinions between genders; however, in common with many other studies, it proved difficult to recruit fathers. Therefore, the range of views presented may not fully represent the views of fathers. It was not possible to determine whether educational level had an independent influence on parents' information seeking as most of the parents with low educational attainment also had low literacy.

Data were collected and analysed by a team including healthcare professionals and non-clinical researchers, some of whom were parents and others not. Their different perspectives and assumptions complemented each other and enabled a richer understanding. For example the non-clinical researcher who co-analysed the data was free from pre-conceived assumptions regarding parents' consultations with HCPs, whilst the HCPs were able to interpret the parents' comments in the context of healthcare encounters. The analysis was also reviewed by parents from our parent panel.

Implications and recommendations

Although there is a wealth of information available for parents to access independently, the findings from this study indicate a need for easy access to clearly signposted, professionally validated resources, available in a range of formats provided through different delivery systems. Self-initiated learning when the threat to self is low, such as in the home environment, has been claimed to be the most lasting and pervasive.[27] One size does not fit all. Audiovisual media, in the right language and the correct form of language, would address the needs of parents with low levels of literacy, but the challenge of signposting any such resources without resorting to written formats remains.

Findings also indicate the need for developments in the provision of information by HCPs during consultations, including: consistent provision of consultation specific supporting information for later reference; changes in consultation behaviour to reduce the anxiety created by social hierarchies; and assessment of parents' knowledge so that information can be appropriately tailored to the individual.

The findings presented here indicate the need for development of new information resources. There is currently a lack of evidence to support the development of effective resources. HCPs are, of course, likely to be key to the dissemination of any new resources, highlighting the need for a collaborative approach. Therefore, in parallel with this study, we undertook a qualitative analysis of the preferences of parents and HCPs regarding the format, content and delivery mechanisms for such resources[34] which, combined with this study, will provide important insight into how to develop effective resources to help parents' decision making when their children are sick at home.

Acknowledgements

assisting with data collection and the PCRN and CLRN for coordinating recruitment. This publication presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0407-10347). Matthew Thompson's & Caroline Jones' contribution to this independent research arose from MT's Career Development Fellowship supported by the National Institute for Health Research (NIHR). Dr. Damian Roland was an NIHR Doctoral Research Fellow at the time the study was performed. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

The study was conceived and designed by SN, ML, DR and MT. SN collected the data. CJ and SN analysed the data. The study was drafted by SN; all authors read and approved the final manuscript.

References

1 Mayall B. *Keeping Children Healthy*. London: Allen & Unwin, 1986.

2 Holme C. Incidence and prevalence of non-specific symptoms and behavioural changes in infants under the age of two years. *British Journal of General Practice*, 1995; **45**: 65–69.

3 Bruijnzeels MA, Foets M, van der Wouden JC, Prins A. Everyday symptoms in childhood: occurrence and general practitioner consultation rates. *British Journal of General Practice*, 1998; **48**: 880–884.

4 Saunders NR, Tennis O, Jacobson S, Gans M, Dick PT. Parents' responses to symptoms of respiratory tract infection in their children. *CMAJ Canadian Medical Association Journal*, 2003; **168**: 25–30.

5 Neill SJ. Containing acute childhood illness within family life: a substantive grounded theory. *Journal of Child Health Care*, 2010; **14**: 327–344.

6 Ehrich K. Reconceptualizing 'inappropriateness': researching multiple moral positions in demand for primary healthcare. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 2003; **7**:109–126.

7 Houston AM, Pickering AJ. 'Do I don't I call the doctor': a qualitative study of parental perceptions of calling the GP out-of-hours. *Health Expectations*, 2000; **3**: 234–242.

8 Neill SJ. *Family Management of Acute Childhood Illness at Home: A Grounded Theory Study [Doctoral]*. London: King's College London, 2008.

9 Williams A, O'Rourke P, Keogh S. Making choices: why parents present to the emergency department for non-urgent care. *Archives of Disease in Childhood*, 2009; **94**: 817–820.

10 Kai J. Parents difficulties and information needs in coping with acute illness in preschool children: a qualitative study. *British Medical Journal*, 1996; **313**: 987–990.

11 Sands R, Shanmugavadivel D, Stephenson T, Wood D. Medical problems presenting to paediatric emergency departments: 10 years on. *Emergency Medicine Journal*, 2012; **29**: 379–382.

12 Hippisley-Cox J, Vinogradova Y. *Final Report to NHS Information Centre and Department of Health: Trends in Consultation Rates in General Practice in England 1995/1996 to 2008/2009: Analysis of the QResearch Database*. London: QResearch and the NHS Information Centre, 2009.

13 Avoiding Purdy S. *Avoiding Hospital Admissions. What Does the Research Evidence say?* London: The Kings Fund, 2010.

14 Royal College of General Practitioners. *RCGP Child Health Strategy 2010–2015*. London: Royal College of General Practitioners, 2010.

15 Royal College of Paediatrics and Child Health, Royal College of General Practitioners, College of Emergency Medicine, *et al.* To Understand and *Improve the Experience of Parents and Carers who Need Assessment When a Child has a Fever (High Temperature)*. London: Royal College of Paediatrics and Child Health, 2010.

16 Bouche G, Migeot V. Parental use of the Internet to seek health information and primary care utilisation for their child: a cross-sectional study. *BMC Public Health*, 2008; **8**: 300.

17 Goldman RD, Macpherson A. Internet health information use and e-mail access by parents attending a paediatric emergency department. *Emergency Medicine Journal*, 2006; **23**: 345–348.

18 Khoo K, Bolt P, Babl FE, Jury S, Goldman RD. Health information seeking by parents in the

Internet age. *Journal of Paediatrics and Child Health*, 2008; **44**: 419–423.

19 Pandolfini C, Impicciatore P, Bonati M. Parents on the web: risks for quality management of cough in children. *Pediatrics*, 2000; **105**: e1.

20 Wainstein BK, Sterling-Levis K, Baker SA, Taitz J, Brydon M. Use of the Internet by parents of paediatric patients. *Journal of Paediatrics and Child Health*, 2006; **42**: 528–532.

21 Stern PN. Using grounded theory method in nursing research. In: Leininger MM (ed.) *Qualitative Research Methods in Nursing*. Orlando, FL: Grune & Stratton, 1985: 149–160.

22 Glaser B, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter, 1967.

23 Glaser BG. *Emergence vs Forcing. Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press, 1992.

24 D'Alessandro DM, Kreiter CD, Kinzer SL, Peterson MW. A randomized controlled trial of an information prescription for pediatric patient education on the internet. *Archives of Pediatrics & Adolescent Medicine*, 2004; **158**: 857–862.

25 Hughes S, Quinn FM. *Quinn's Principles and Practice of Nurse Education*, 5th edn. Andover, UK: Cengage Learning, 2007.

26 Rogers A. *Adults Learning for Development*. London: Cassell Education, 1992.

27 Rogers C. *Freedom to Learn*. Columbus, OH: Merrill, 1969.

28 Mosa ASM, Yoo I, Sheets L. A systematic review of healthcare applications for smartphones. *BMC Medical Informatics and Decision Making*, 2012; **12**: 1–31.

29 Neill SJ, Cowley S, Williams C. The role of felt or enacted criticism in understanding parent's help seeking in acute childhood illness at home: a grounded theory study. *International Journal of Nursing Studies*, 2013; **50**: 757–767.

30 Stigma GE. *Notes on the Management of Spoiled Identity*. London: Penguin, 1963.

31 Goffman E. *Interaction Ritual. Essays on Face-to-Face Behaviour*. Harmondsworth: Penguin, 1972.

32 Curzon LB. *Teaching in Further Education: An Outline of Principles and Practice*. London: Continuum International Publishing Group Ltd., 2003.

33 Smith D, Ruston A. 'If you feel that nobody wants you you'll withdraw into your own': gypsies/Travellers, networks and healthcare utilisation. *Sociology of Health & Illness*, 2013; **35**: 1196–1210. On line first 10 APR 2013.

34 Jones CHD, Neill S, Lakhanpaul M, Roland D, Singlehurst-Mooney H, Thompson M. Information needs of parents for acute childhood illness: determining 'what, how, where and when' of safety netting using a qualitative exploration with parents and clinicians. *BMJ Open*, 2014; **4**: e003874.