

E-health and health care behaviour of parents of young children: a qualitative study

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ABSTRACT

Objective: Internet plays a huge role in providing information about health care problems. However, it is unknown how parents use and perceive the internet as a source of information and how this influences health care utilisation when it comes to common complaints in infants. The objective was to evaluate the perception parents have on the role of internet in providing health care information on common symptoms in infants and its effects on health care utilisation.

Design: A qualitative design was chosen. **Setting and subjects:** Parents were recruited from a population-based birth-cohort and selected purposefully. **Main outcome measures:** Semi-structured interviews were used to receive information of parents' ideas. Thematic coding and constant comparison were used for interview transcript analysis. **Results:** Ten parents were interviewed. Parents felt anxious and responsible when their child displayed common symptoms, and appeared to be in need of information. They tried to obtain information from relatives, but more so from the internet, because of its accessibility. Nevertheless, information found on the internet had several limitations, evoked new doubts and insecurity and although parents compared information from multiple sources, only the physician was able to take away the insecurity. The internet did not interfere in the decision to consult the physician. **Conclusions:** Parents need information about their children's symptoms and the internet is a major resource. However, only physicians could take away their symptom-related doubts and insecurities and internet information did not play a role in parental decision making. Information gathered online may complement the information from physicians, rather than replace it.

KEY POINTS

- Internet plays an increasing role in providing health care information but it is unknown how this influences health care utilisation.
- Our study suggests that:
- Parents need information about their children's symptoms and the internet is a major resource.
- However, only physicians could take away their symptom-related doubts and insecurities.
- Internet information did not play a role in parental decision making.

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Introduction

The internet is increasingly used as a health information resource because of its enormous amount of information, wide availability, 24-hour-a day accessibility and anonymity.[1–4]

People use the internet for different reasons, such as finding information about healthy lifestyles, but also for gathering information when they experience symptoms or finding extra information after a consultation.[5,6]

Almost half of all patients consult the internet before going to see a physician.[7] Around 70% of adults report seeking health related information on the internet,[8] however parents, and especially mothers of infants are even more likely to consult the internet for health-information.[9–11] Still, parents indicate that it can be difficult to find reliable information and some studies show that websites give advice and recommendations that deviate, to various degrees, from the

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recommendations in the general medical guidelines.[11,12] Infants experience numerous common symptoms and while most of these symptoms are harmless and self-limiting, parents of infants report feeling disempowered and anxious and primary care consultation rates for these symptoms are therefore high.[13,14] One could hypothesize that online health information provides the desired knowledge, reassures parents and thereby influences health behaviour and health care utilisation. On the other hand, some studies suggest that physicians are still seen as the most important source of health information[15,16] and that information gathered online may complement the information from physicians, rather than replace it.[17] Although more and more health institutes make online programs and offer online facilities that provide information that otherwise would be provided by a physician,[18] there is only sparse information about the way in which internet information influences whether people consult a physician for common symptoms. Most of these data has been collected retrospectively, and the studies show contradictory results.[19–24] No randomized controlled trials have been performed to investigate this, and only two studies are performed with regard to child health care.[19,21] Before large scale implementation of internet programs with health information on common symptoms in infants, a more detailed understanding of the way information found on the internet influences health care behaviour in the

general population is necessary. We designed a qualitative study on parents' experiences and perceptions of the use of internet information for common health-related problems in their infants. The aim of this study is to explore in what way parents of infants use information from the internet when their infant displays common symptoms, whether and what information on the internet can reassure parents and if this information influences health care utilisation.

Materials and methods

Participants

Participants were recruited from a large population-based birth cohort on respiratory illnesses in children that started in December 2001, the Wheezing Illness Study Leidsche Rijn (WHISTLER).[25] The study takes place in Leidsche Rijn, a new area near the city of Utrecht, The Netherlands. All children born in the area from 2001 to 2012 were invited to participate. From December 2011 until February 2012, ten parents, of children that just reached the age of one year, were asked to participate in this explorative qualitative study, and all parents agreed. Parents were purposefully selected such that variety was ensured with respect to: gender of the infant, educational level, the presence of older siblings, and their infant's respiratory symptoms in the first year of life (Table 1). This study has been approved by the medical ethical committee of our hospital and all parents gave written informed consent.

Data-collection

A qualitative design was used. Data were gathered by individual semi-structured interviews using an interview guide (Table 2). It was explained to the parents that the questions could be applied to several common symptoms in infants, like fever, earache, coughing, rhinorrhoea, diarrhoea, eczema; whatever applicable. One person performed all the interviews (AG). Appointments

Table 1. Parent and infant characteristics.

Characteristic	
<i>Parent (n = 10)</i>	
• Interviewed mothers n (%)	9 (90)
• Age of interviewed parent, years (sd)	31.7 (3.1)
• Higher education ^a n (%)	5 (50)
• Western ethnicity n (%)	9 (90)
<i>Infant</i>	
• Number of boys n (%)	5 (50)
• Age of child in the study months (sd)	16.1 (2.0)
• First child n (%)	6 (60)
• Significant respiratory symptoms in first year n (%)	4 (40)

Sd = standard deviation.

^aHigher vocational or university education.

Table 2. Checklist of the interview: general overview.

<i>Acting when infant is ill</i>
• Reaction (e.g., what do you do when your infant is ill?)
• Information need (e.g., what information do you need when your infant displays symptoms?)
• Information sources (e.g., what information sources do you use for health care information?)
<i>Internet information</i>
• Availability (e.g., how do you judge the availability of online health information?)
• Reliability (e.g., how do you consider the reliability of online health information?)
• Benefits and drawbacks of internet information (e.g., what are the most important benefits/drawbacks of internet information?)
• Desires (e.g., what [kind of] information is lacking on the internet according to you?)
<i>Information and health care utilisation</i>
• Purpose of information seeking (e.g., what is the main reason for pursuing information?)
• Role of internet information (e.g., according to you, what is the role of online health information for health care problems in infants?)
• Influence on health care utilisation (e.g., in what way do you think that the use of internet information influences your health care utilisation?)
• Role of the physician (e.g., what is the role of the physician compared to internet information?)
<i>Other information</i>
• Other relevant information (e.g., what else do you think is important for me to know?)

Table 3. Parental duty in taking care of their infant: main issues.

Vulnerability of infants	<i>"With a infant you should take symptoms seriously. I mean, a infant is very fragile, when a infant has symptoms, you have to go to the physician to obtain information".</i>
Developing a frame of reference	<i>"eehmm, yes, so you want to know whether something is normal and especially if it is self-limiting, or whether you should treat it, whether you should use medication or not. And of course when you should consult a physician, how serious the symptoms are and in what way they can evolve".</i>
Responsibility to know the limits of own capabilities	<i>"I think I'm at the point now that I can tell whether or not I should consult a physician, but in the first year we consulted the general practitioner a couple of times when we just didn't know exactly what was going on. And eh, then you end up going home with nothing achieved, because there was nothing alarming going on actually".</i>
Minimising the risks/rule out serious disease	<i>"Shortly after her birth Julia became very ill, and in that case I didn't need to think twice before acting and did so within an hour. I do think that was also because of our experience with Tom; he suddenly, with very little warning became very ill and so now it was almost routine to immediately call for help".</i>
Sharing responsibility	<i>"I was really happy that she was there in the hospital, and I have to say on the way to Woerden we had both thought we won't leave until she has seen a doctor and we will just refuse to take her back home with us, because the situation was just unmanageable".</i>

were made and parents were visited at their home. The visits were independent of actual symptoms of the infant.

The main objective of this study was to inquire for parents' perceptions on the use of internet, the way internet had met their needs, and the way internet information had influenced health care utilisation. The wording of the questions was as open as possible. The interviews were audiotaped, and transcribed verbatim, except for names, which were substituted to remove identifying information. The interviews lasted 27 min on average (range 13–37 min).

Data analysis

All data were collected prior to analysis. The analysis was carried out according to the constant comparison method.[26] The analysis was structured in line with the process described in the Qualitative Analysis Guide Of Leuven (QUAGOL).[27] Coding and code tree development was supported by Nvivo (version 9, QSR International, Melbourne, Australia). AG and MK independently coded the first three transcripts and differences were discussed until consensus was reached. Subsequent interviews were coded by AG and checked by MK. New interviews were compared with existing codes to identify similarities and differences. The codes were grouped into categories. Theoretical saturation was reached with respect to the identified themes. RL reviewed and approved the analysis.

Results

We identified four themes that provided insight into the queries we had; the duty that parents feel in taking care of their infant; internet providing an extra opinion; the uncertainties of information found on internet; and lastly, the irreplaceability of the physician.

The duty of parents in taking care of their infant

Parents appeared to experience a specific sense of duty to take care of their infant when it was experiencing common symptoms (Table 3). The main reason for this was that they considered their infants to be very fragile and susceptible. Parents reported feeling uncertain and feared that the illness would escalate. They felt highly responsible to act correctly and they worried that they might otherwise cause their infant unnecessary suffering or even feared losing it because of their inappropriate course of action. Parents especially described the first year of life as a different period, compared with the period thereafter. After the first year of life they regarded their child as less vulnerable and parents were more familiar with the way their child reacted when it was ill. Parents needed to develop a frame of reference and needed to learn when they could handle the symptoms of their infant themselves, and when they needed to call upon the help of a physician. They did not want to take a risk with their infant. During times of illness in their infant, parents tried to minimise the risk that the symptoms would develop into severe illness. They looked for ways to resolve their insecurity and to share responsibility.

Internet providing an extra opinion

Parents appeared to be in great need of information when their infant displayed symptoms (Table 4). All parents reported that they were looking for information, especially when symptoms were new and unknown. They searched to obtain information on different subjects: what are normal symptoms in infants of this age, what could cause the symptoms, and how they were supposed to act. Information helped parents in fulfilling the duties they felt when their infant displayed common symptoms, like minimizing the risks, and in removing insecurity. Information was acquired

Table 4. Internet providing an extra opinion: main issues.

Information need	<i>"When I think, I don't know what this is, or this is new, like teething, then I start 'googling'".</i>
Extra opinion	<i>"Searching the internet is the first step, to try to find information on what it could be, or calling my sister in law who is experienced because she already has 3 children, and the oldest is already ten. Or calling my own mother".</i>
Increased disease understanding	<i>"Yes, at that moment [during the first year] I used the internet more often, to find out whether I worried too much, or whether I had to do something. And then I was more in want of tips and tricks, what I could do in any given situation".</i>
Confirmation of own ideas	<i>"I always search the internet first to try to find some advice, or to try to find information that confirms what I suspected was going on".</i>
Looking for reassurance	<i>"I'm searching for reassurance I think, I want to know what is going on, what it might be and what the course of the symptoms will be for example, and I don't want to have that doubtful feeling and worry about what it is and what I have to do with it".</i>
Paying attention to their infant	<i>"For her I searched a lot on the internet, she had such a bad barking cough. I was searching for what it could be, just because I was interested and maybe I could help her in some way".</i>

Table 5. The uncertainties of information found on the internet: main issues.

Uncertainty whether information was reliable and correct	<i>"Usually I check the background. I try to find out whether there is a physician involved, I always check that, and I compare multiple sites. I compare whether they contradict or provide consistent information. That's what I also do. I check multiple sites and also whether there's a physician involved".</i>
Uncertainty whether their infant indeed had what they read	<i>"At that moment it is very hard to reassure yourself, because you don't know if your infant has the same as what they describe or what their infants had".</i>
Information could be frightening	<i>"And eh, then we did some searching on the internet, but you actually shouldn't do that. Because you read a lot of strange stories".</i>
Internet could reassure unjustly	<i>"You can be misled. People can describe things that have not been investigated properly. You may get an incorrect explanation. And then consult a physician too late. They are reassured by the things they read. I think that's a disadvantage".</i>
No restriction of information	<i>"I prefer it when you receive the main information first and are then able to find more information if you want. I really like that. And that you don't see all those horrible scenarios that you find quite easily on the internet, I think no body is happy with that. What I want to know is when you should take action. For example when there's a temperature above 40 degrees, then go to the doctor. But then the information should stop, because then you consult the doctor, and the doctor will take it from there. Because otherwise everyone panic's because of all the possible horror scenarios".</i>
Internet and health care utilisation	<i>"I really liked it that it confirmed my own ideas, but internet never determined whether I would or wouldn't go to the doctor. Never".</i> <i>"I always search the internet at first. After that I would consult the doctor, but I use the internet more like reference, just to know what the internet says".</i>

from experienced friends, neighbours, or family, and from the internet. Information found on the internet appeared to be an extra opinion, alongside other sources. While parents sometimes found it cumbersome to approach relatives; internet was easily accessible 24 h a day and had the advantage of containing an enormous amount of information. Information found on the internet helped in developing a frame of reference, and increasing understanding of disease. The main objectives of looking for information were finding reassurance and confirming own ideas. It turned out that parents usually had specific ideas about their child's condition, and were looking for confirmation of their own ideas on the internet. Searching for information appeared to give parents a feeling of usefulness and the satisfaction that they could be meaningful to infant while it was ill.

The uncertainties of information found on internet

Searching information on the internet also had limitations (Table 5). Parents indicated that they frequently

doubted whether to believe the information or not. They also never knew exactly who wrote the information they found. Another fear was to become unjustly reassured, while the infant was in reality very ill. To minimise these limitations and maximise the reliability of the obtained information, many parents sought out the background of an internet site. Parents preferred a medical institution or organisation as an information source. They even more so appreciated a site from a trusted and known physician, such as their own general practitioner. Parents also frequently compared the information they found to information from other sites or sources. Some parents turned out to check and compare multiple sites and reported a greater trust of online health information when it was repeatedly found. However, the enormous amount of information also had important drawbacks. Parents were often overwhelmed by the available information and found it very difficult to find a reliable answer. Information also evoked new insecurities and doubts. Some parents reported becoming anxious because on internet they found information on all severe and rare diseases that could be the cause of the

Table 6. The irreplaceability of the physician: main issues.

Face to face contact
<i>"Internet sites and programs can't see my infant, so that's the problem, if they have a skin rash for example, or it looks like it, I want the confirmation from the GP. I want to have that certainty".</i>
Reassurance
<i>"I'm only reassured when I've consulted a physician who is experienced in his field and who knows what is going on and how to act".</i>
Tailor-made information
<i>"No, I mean, the GP is nearby, I want to continue consulting him, and I prefer face-to-face contact, unless it is something not important, but usually, the GP is near and he can see him immediately. Maybe there's something else going on and then he can diagnose that straight away".</i>
Main information source
<i>"Now I do read it [internet information about asthma] more intended for Tom. First I read it for myself, but at this moment I'm doing fine actually. So now I read it more for Tom. What are the last studies etc. But internet gives more side-line information, for the main information I consult a physician".</i>

same specific symptoms. Parents stressed that information found on the internet did not take into account the whole context and background of an infant and of a family. Therefore, internet did not restrict information to the exact situation, but gave general and broad information. Parents preferred tailor-made information, focusing on their actual situation. Therefore, they considered it necessary that a physician assessed their infant and heard their story. According to most parents, information found on the internet sometimes postponed a doctor's consultation, but in their opinion it hardly influenced their health care utilisation. Parents said to have their own opinion about the situation and had often already decided whether they wanted to consult a physician or not before searching the internet. This decision was made, based on their own judgement, independently of the information they found on the internet or heard from others.

The irreplaceability of the physician

Although parents were looking for reassurance on the internet, they indicated that only a "face to face" consult with the physician could give complete reassurance (Table 6). According to the parents the physician was the only one who could assess the symptoms in the whole context of the infant. The physician had the capability to examine the infant, evaluate the situation and act directly if necessary. The physician was able to provide tailored information, could oversee the complete picture of complaints, including matters they hadn't paid attention to. According to the parents, information gathered online may complement the information from physicians, rather than replace it. One mother described the physician to be "the main source of information", while information found on internet was seen as additional information. Some parents discussed the use of a chat-function with the physician; but found that this would reduce the physician into the same category as "internet" or "their neighbours"; someone unable to see the infant and evaluate the whole situation. For some parents internet appeared to have a role after consulting a physician. It

provided additional information and was also used as an additional check on the information received. Other parents described that internet made a consultation more effective and efficient.

Discussion

The purpose of the current study was to strengthen our knowledge of parental opinions on the role of internet in providing health care information on common symptoms in infants, and the way in which this information can influence health care utilisation. Our study showed that parents appeared to be in need of information when their infant displayed symptoms, and because of its easy accessibility internet was a major source of information. However, the information parents found on the internet did not influence their health care utilisation. The decision to consult the physician was based on parents' own common sense and internet did not appear to interfere with this. Only the physician could resolve their uncertainty and rule out potential risks.

There are some considerations to be made when interpreting these results. Firstly, we interviewed parents participating in the WHISTLER-project with a relatively high socio-economic status. Most of them were female with a western ethnicity. Therefore, our findings might not be generalizable to the general population. Secondly, we only performed ten interviews. However, despite this small number there was remarkable agreement between the different parents concerning the inability for the internet to replace face-to-face contact with the physician. We realise that our results are just a starting point, a first step in the unravelling of the way the internet is used. We do not know whether in other cultures or rural areas, parents would react differently. It would be very interesting to study this question also in populations, for example in other countries.

We decided to focus on several common symptoms in infants, like fever, earache, coughing, rhinorrhoea, diarrhoea, eczema; whatever applicable. It has been described that during the pre-school years, all children experienced one or more symptoms, mostly fever, and respiratory or gastro-intestinal symptoms and 97%

consulted a doctor at least once.[14] In most cases, these symptoms are self-limiting. To our opinion, the acting of parents when their infants display one of these common symptoms, does not differ so much between these symptoms.

Studies investigating parents' opinions on the use of information found on the internet, for common symptoms in infants, and the way in which this influenced their health care utilisation are lacking. Due to the large amount of information that can be found on the internet, the high percentage of parents who are using the internet for health care information,[9–11] and the usually self-limiting nature of symptoms in infants, it was suggested that this may influence their decision whether or not to consult a physician. However, this study indicated that the decision to consult a physician appeared to be already made before consulting the internet and whatever information was found did not influence this decision. Quantitative, cross-sectional studies that investigated the association between internet usage and health care utilisation, found inconsistent results. In one of them it was also suggested that the internet is used as a supplement to conventional health care rather than as a replacement.[19] Parents used information found on the internet as an extra opinion and although they preferred to use sites originating from reliable clinical professionals, they still only regarded these sites as valuable as the opinion of experienced relatives, instead of the level of physicians. This agrees with a study that investigated the role of internet in making common medical decisions including prescription requests, cancer screening, and elective surgery. The authors also found that only a minority of patients reported using the internet in making decisions.[28] Health care utilisation could only be influenced by internet when the online information could reassure parents. Parents were frequently insecure about the reliability and background of the information. A previous study showed that people usually omit to check the origin of information found on the internet.[29] Our study indicated that parents value the background and prefer information from medical organisations and clinical professionals. Infants are considered to be very fragile and parents fear symptoms might easily escalate to severe illness. As internet doesn't "see" the infant, parents are never certain that their infant indeed has the condition or disease that is described and as a result this cannot reassure them. Also parents wish to share the responsibility involved in concluding that symptoms are harmless. They consult because they want to rule out serious disease. A study which investigated the motivation for parents to seek "after hours" primary care for their children found

that once their anxiety had escalated to a certain level, parents needed a consultation with a doctor to resolve it.[30] Face-to-face contact with a physician is crucial. Advances in information technology have thus far not fundamentally changed the very essence of doctor–patient consultations.[31]

The question is whether online information can ever substitute health care utilisation. Future research should investigate whether online contact with a physician, for example screen to screen communication, could be a tool that would influence behaviour. Another possibility is to investigate whether internet-based information is more accepted if received in non-stressful situations. Internet information fails to reassure parents when their infant has symptoms but it may be more of use if parents are informed about symptoms prior to illness of the child. It is important to study whether general information provided at an early stage, for example, by the child health care centres, could sufficiently inform parents about general symptoms that are likely to occur in all infants. Parents should be informed that although symptoms can influence daily life, wheezing and coughing are physiologically normal phenomena in the growing and developing infant and the majority of symptoms will be self-limiting. With a timely intervention it might be possible to manage expectations, change behaviour, and reduce health care utilisation when an infant has symptoms.

The future will also show whether the next generation, raised with online communities and social networks, will be more comfortable to use online health information in their decision-making.

This study showed that parents of infants frequently look for online health information when their infant experiences common symptoms. This information is additional to primary health care and it is not necessarily utilized in the decision-making process whether or not to consult a physician.

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Ethical approval

The study was approved by the local medical ethics committee (UMC Utrecht) and all the parents signed for informed consent.

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