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RESEARCH ARTICLE (PEER REVIEWED)

Building health knowledge online: Parents' online information searching on congenital heart defects

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Abstract

The study examines online searching as a digital health literacy practice and focuses on parents of children with congenital heart defects. Over the period of four years, we have conducted interviews with couples at different stages of pregnancy or parenthood and have encouraged them to reflect on their literacy practices when receiving a heart defect diagnosis, during the remaining time of their pregnancy and when living with a child with a heart defect. We have also read and analysed health blogs written by parents and focused on extracts where literacy events are described. Searching for information and support online is one of the most frequent practices amongst the participants in the study. The aim of this paper is therefore to highlight the complexity of looking for information online in order to take health decisions and provide care to a child with congenital illness. Based on what parents say they do when searching online, we focus on three main paths to knowledge: looking for medical facts, looking for other parents' experiences and looking for practical information. We discuss digital health literacy practices as complex activities that often involve parents in the diagnosis and in the child's medical care to such an extent that parents build up knowledge and become experts, not only in finding information and support but in talking and writing about their child's illness. We also problematise the notion of trustworthy health information and show how facts and opinions often go hand in hand in platforms where health issues are discussed.

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Finally, we show some of the affordances and restrictions inherent in using the internet as a source for meaning making and learning about children's health. The results reinforce our understanding of the socially framed nature of health literacy and make us focus on the digital as an additional important aspect in the practice of health literacy.

1. Introduction

Searching for health related information online has become an established practice of health literacy and using the internet for both knowledge building and interaction is now the norm (e.g. Miller and Pole 2010, Hu and Sundar 2010, Rains and Keating 2015). This study concerns self-initiated information seeking processes that exist outside but in close relation to an institutional framework. We take a closer look at digital health literacy practices as situated phenomena by focusing on what parents say they do when looking for information related to their child's illness. Information is here defined as *medical*, *experiential* or *practical* content, and we are interested in the functions that this content fulfil, e.g. *informing* and *supporting* the parent.

The study presented here is part of a Swedish linguistic research project called Health Literacy and Knowledge Formation in the Information Society. The project investigates parents' discursive constructions of knowledge after their child has been diagnosed with a prenatal heart defect. In Sweden, such defects are in many cases discovered in a routine ultrasound screening (RUL) offered between weeks 18 and 19 of the pregnancy (Bergman et al 2008). A few days after the RUL the pregnant couple is scheduled for an appointment with a cardiologist. After the initial consultation, fetal cardiology follow-up is offered every four to six weeks to observe the progression of the heart defect, prepare the couple for the birth and if needed, plan for surgery during the first postnatal week. The fact that the couples are given a great deal of information in a fairly short time is one of the reasons that many of them use the internet as a major source of further information after the consultation (Carlsson et al 2015a).

The aim of this study is to examine searching online for information related to children's health as a digital health literacy practice. We want to understand why the parents turn to the internet and what they look to find, as well as what attitudes they have to the information they find. We also want to discuss affordances and restrictions in engaging in health literacy practices online, and the way they are experienced by the parents in our study. We make the complexity of online literacy practices visible by analysing interviews with pregnant couples who have received a heart defect diagnosis about their baby's health, and with parents of children with heart defects. A second source of data are blogs where parents of children with heart defects write about their online searching practices.

2. Health literacy and digital health literacy

Within medical research, the concept of health literacy is often treated as an individual capacity to take personal responsibility for one's own health and wellbeing (e.g. DeWalt et al 2004, Berkman et al 2011). The importance of individuals being literate in order to 'read' health messages, make choices about their usefulness and act on them are often stressed. Poor health literacy is associated with individuals, or groups of individuals, having difficulties in engaging in preventive health care practices, in detecting disease early and in accessing primary health care such as visiting a doctor (Green, Bianco and Wyn 2007). Studies on health literacy often focus on measuring and judging literacy rates using, for example, The Communicative

and Critical Health Literacy Scale, and the eHealth Literacy Scale (eHEALS). Seen from this skill-oriented perspective, people with low literacy are at a higher risk of disease, injury and death compared to people with more advanced literacy skills. By placing the study in the paradigms of New Literacy Studies (NLS) (e.g. Barton 1994, Street 1984) and information literacy (e.g. McKenzie 2002, Papen 2013), we replace the skill-oriented perspective of learning about health with a social perspective where health literacy is understood as knowledge building and meaning-making processes, performed as social activities situated in time and in place (see Dray and Papen 2004). Looking for and accessing information about one's condition does not lead to an isolated act of acquisition of skills and knowledge related to health. Instead as research has shown, health literacy presents complex cognitive, social, cultural and affective challenges for patients at multiple levels (e.g. Green, Bianco and Wyn 2007, Papen 2009, Hunter and Franken 2012). The knowledge gained is put in use by patients (or in this case parents) in order to take decisions (see Yeoman 2010), provide care (to themselves or to others) and participate in, for them, meaningful communication with the medical staff. The information seeking practices are grounded in patients' needs and often lead to new concrete actions.

A significant shift in the field of NLS is *the digital turn* (Mills 2010:246), which followed what Gee characterised as the *social turn* (1996) in literacy research and a consequence of globalization and technical developments in society (Mills 2010). *Digital literacies* are defined by Barton and Gillens (2009:9) as: 'the constantly changing practices through which people make traceable meanings using digital technologies'. The concept is an extension of the concepts from NLS, but with a clear focus on digital technologies, and the way they affect interaction with digital texts and the meaning making processes that are included in this interaction.

In the fields of medical informatics and public health the term eHealth has been used for almost twenty years in order to describe institutional practices for developing the connection between health care information and communication technology (Eysenbach 2001). When making reference to individuals' practices (as opposed to institutional practices) the term eHealth literacy is used and it describes: 'the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem' (Norman and Skinner 2006:2). The same researchers discuss six core skills that when combined lead to eHealth literacy: traditional literacy, health literacy, information literacy, scientific literacy and computer literacy. For Norman and Skinner core skills are seen as synonymous to literacies but they need to preexist in individuals in order for them to engage in successful eHealth literacy. We find this notion problematic and want instead to discuss digital health literacy as a set of practices in which patients (in this case parents) engage without necessarily having pre-existing knowledge. Instead we want to show how parents build up new experiences and acquire new knowledge in the process of practicing digital literacy (see Barton 2010, Gillen 2014). In this study, we show examples of digital health literacy where literacy is a broader concept than reading and writing practices and is discussed as processes of building up knowledge.

3. An ethnographic approach

The use of ethnographic methods to study digital literacies has often been considered difficult compared to traditional (offline) ethnography. Since internet users often move quickly between different websites and different digital activities it can be a real challenge for researchers to identify literacy practices especially when the object of study is not limited to one specific

digital platform but to a theme that can take numerous expressions in the digital world (Leander 2008). The participants in our study draw upon digital activities when they feel the need to find information. This means that their search activities are spread out over days, they alternate between using computers, tablets and mobile phones, and they perform searches for health information from their work, the bus or even their bed. Nor is the time they spend doing online searches restricted to a specific period of time, for example only on the days after the initial consultation with the cardiologist.

In order to address these difficulties, we had to be creative and use several methods that would bring us closer to parents' online searches. One way was to perform in-depth narrative interviews (Mishler 1984) with pregnant couples and parents, where we asked them to reflect on their information searching practices throughout their pregnancy and in the child's early childhood. We used interview questions such as 'tell us about...' to promote narratives, for example 'tell us about how you handled the information the doctor gave after the scan'. An additional source of information for the study are blogs written by parents of children with heart defects. The sequences that we have chosen to use from the blogs are reflective accounts on searching for health related information and they include the same kind of narratives as the ones found in the interviews. In a way, the blogs come closer to parents' online searches than the interviews since they are often reported in real time in the form of a diary. Mortensen (2014) discusses blogging as a hybrid product resulting from all previous kinds of personal writing (e.g. diary) and one that inevitably contains meta-reflection. It is on this feature that we base our data searches in the blogs, by looking for sections where parents discuss information they have found on the internet and reflect on the path they followed in order to access it. Health blogging has become popular during the recent years and some of the reasons are that blogging gives opportunities to vent problems and to receive support and advice from readers at the same time as it reaches out to others in need (Bellander 2016, Pettigrew, Archer and Harrigan 2016). Writing health blogs has been described as similar to expressive writing as health bloggers are articulating their experiences during a traumatic life event (Sundar et al 2007).

Our interest in following the participants' digital practices and the role they play in parents' social practices ties this study to the methodological field of *connective ethnography* (Leander 2008). This term describes an orientation to internet-related research that seeks for connections between online and offline social spaces. The parents' online searches for information related to their child's heart-defect often lead them to take action in their lives offline, at the same time as social practices they experience in everyday life lead them to participation in online social spaces.

4. Research participants and methods of analysis

As this study's goal has been to capture the complexity of the literacy practices generated when having a child with a heart defect, our data vary to a great extent. We have recorded and transcribed 25 in-depth interviews where we have used open questions that enabled the participants to reflect on their searches for information on congenital heart defects as a social practice. The interviews were between 30 minutes and one hour long and were carried out between the years of 2013–2016. We were able to get in contact with most of the participants in the study through our project's close collaboration with medical professionals at two of the largest hospitals in central Sweden. Some participants were contacted through their blogs where they had left their contact information. All participants were given oral and written information about the research project and signed their agreement to participate in the

recorded interviews. All personal names and dates have been changed in the extracts shown in the article, and names of places have been replaced with explanations in brackets.

The participants were aged approximately between 25 and 50 years old. They live spread in many counties in central Sweden and they have different economic, educational and sociocultural backgrounds. Three of them are multilingual and use either Arabic, German or Thai besides Swedish in their families. All participants understand and use spoken and written English in their daily lives. English is a widely spoken foreign language in Sweden and most citizens (89 percent of the population according to an EU-report in 2012), master it well enough to have a conversation, while 71 percent use English at a regular basis on the internet. Some of the participants in the study were pregnant during the interview and some were parents of infants or toddlers. We also met two couples who had terminated their pregnancies after a diagnosis of a heart defect in their foetus. Most of the participants had received the diagnosis during RUL halfway in their pregnancy but some had found out right before or right after birth. The fact that the interviews had been conducted at different stages of the participants' pregnancies or parenthood meant that they all brought different viewpoints when discussing their digital health literacies. Pregnant couples were able to talk about their online searches in real time, whereas couples that had terminated the pregnancy looked at their health literacy practices in retrospect. The parents had the experience of going through the different stages of treatment; some had children who had gone through one or more heart surgeries and others had surgeries ahead of them. Again, this meant that the participants could provide different stories about their digital health literacy practices, depending not least on the temporal differences in their experiences.

We also analysed meta-reflections from 12 blogs written by parents of children with heart defects. Like the interviewed participants, the blogging parents were aged between 25 and 50 years old and their social backgrounds varied to a great extent. All bloggers except for one were female. All blogs represented a personal journal type health blog in the sense that they describe the experiences of living with a specific disease (Miller and Pole 2010). Similar to most health blogs, they contain long personal narratives and accounts of personal experiences (Kim and Chung 2007). Some blogs in the data started with the aim to tell the story of a specific child's heart disease and some blogs started with a different focus and became blogs about their child's heart disease in the process.

The software Atlas.ti (Paulus and Lester 2015) was used to code transcriptions of interviews and blog content. In an initial analytical stage, we searched the data by marking sections in the interview transcripts and blogs where the participants talked or wrote about searching, googling and reading. As a second step in the analysis we coded segments in the selected sections where the participants talked or wrote about their online searching, i.e. what content they searched for, what type of websites they used and when and where they did their searching.

5. Paths to knowledge in online searching

The parents in this study engaged in online searching as a means of finding information and building up knowledge on two themes: *heart defect* and *taking care of a child with a heart defect*. These knowledge objects are large and therefore there seemed to be various ways to approach them. Participants' search efforts could be rather vague, using keywords such as 'heart defect' or 'hole in the heart'. This often resulted in endless possibilities for information gathering. In other cases, participants looked for concrete answers to a specific question and their

searches were thus more focused. Some were not aware of what paths they had taken when accumulating information and learning on their child's heart defect, whereas others seemed to have designed strategies and only approached the knowledge object from specific points of view, thus discarding some paths to knowledge in favour of others.

We present our analysis by discussing three of the most dominant ways that the parents in the study used when approaching their knowledge objects, whether these were rather vague and large, e.g. life with a child carrying a heart defect, or concrete and focused, e.g. operating a heart. The three common ways of approaching knowledge when our participants were searching online are: *looking for medical expertise*, *looking for others' experiences* and *looking for practical information*.

6. Looking for medical expertise

The first indication of a possible heart defect is presented during the routine ultrasound (RUL) in pregnancy between weeks 18 and 19. Usually the nurses performing the RUL are not equipped to give the pregnant woman more information other than that they do not see a normal heart (see Karlsson, Melander Marttala and Mattsson 2014). The couples are scheduled for a detailed ultrasound examination and a consultation with a cardiologist a few days after the RUL. When recalling the stage between the RUL and the appointment with the cardiologist, many participants in the study expressed a need of turning to the internet for more information.

During an interview a mother, Susanna, wrote down some of the keywords she used when googling: 'Deformation of foetal heart', 'Discovering heart-defect ultrasound', 'Enlarged heart', 'Chances of getting pregnant after termination' and 'Late abortion after diagnostics'. Susanna's list of keywords shows that she, at this stage, used the internet to build up knowledge on two different topics: foetal heart defects and abortion. Because the information from RUL had been inadequate, Susanna's searches were rather broad. During this short period, she knew that something was wrong with the foetus' heart but she had no details about the severity of the anomaly or the prognoses. Like most participants in the study, she recalled feelings of uncertainty and confusion after RUL. Online searches at this stage seem to be used as attempts to prepare for the consultation with the cardiologist. Some participants in the interviews talked about reading at this early stage about children with heart defects, for example in blogs, as a way of preparing for becoming a parent to a child with special needs.

The consultation with the child cardiologist that follows the RUL usually gives the participants more knowledge although a definite diagnosis can sometimes be difficult to give (Bergman et al 2008). A detailed ultrasound is performed followed by a consultation where the cardiologist explains the features of the heart anomaly. (S)he draws sketches of two hearts: one normal heart and one with defect(s). Arrows pointing out the blood flow are drawn and the names of the defect(s) are written on the sketch. The cardiologist also gives information on possible surgical treatment as well as relevant information regarding termination of the pregnancy (Carlsson et al 2015b). In cases where corrective heart surgery can be offered, the majority of Swedish women choose to continue their pregnancy. Termination of the pregnancy has predominantly been due to the most severe cases of heart defects (Bergman et al 2008). Usually the pregnant couples are offered to take the drawings from the consultation home with them and some use the medical terms on the sketch as keywords for further online searches, e.g. 'VSD, ventricle septum defect', 'Tetralogy anomaly' or 'HLHS, hypoplastic left heart syndrome'. Finding relevant information still can still, at this stage, be perceived as problematic

since diagnoses are often both uncertain and complex. In an interview, the couple Marcus and Rachel reflected on how the complexity of the diagnosis affected their attempts to find further information online:

Marcus: and after we got to know what was wrong, it was several things we looked for, we searched 'hole in the valve', we searched 'the flap on septum', we searched 'right ventricle is too small' but we didn't really understand since most of them had small left ventricle and right flap, and as I said, it wasn't exactly what we had, we couldn't find anyone with the exact same defect that we had.

Interviewer: the combination you had been given, what the defects were.

Rachel: Yes exactly I was looking for, oh well, maybe it's called tricuspid atresia or maybe it's called like that, there were a lot of maybes.

The extract illustrates how the couple made use of different combinations of medical terms in order to find the correct information about a heart defect. Other problems found in our data were difficulties understanding the medical descriptions of heart defects. Rachel reflected on this difficulty:

Rachel: All sorts of strange Latin terms that my husband didn't understand, he hasn't studied biology but he just said 'a hole in the valve' and I thought, God, this belongs to the course in physiology that I took. I thought the pages were weird I didn't understand anything.

Rachel claimed that the online information they found after the consultation with the cardiologist was presented using jargon such that it was to them inaccessible. She believed that searching for medical information online could imply having to recall knowledge from high level formal education. To this end, advanced medical descriptions available online seem to sometimes restrict, or simply not significantly contribute, to parents' knowledge construction. The parents' complaints about finding relevant and accessible information can be confirmed by a study in medical research, where the content of websites with information on children's congenital heart defects was analysed and a majority of them were judged as inadequate in terms of, amongst others, currency, content production and ability to engage the reader (Carlsson et al, 2015a).

Other parents described the medical keywords provided by the cardiologist as an affordance, since they used them as starting points for further online searches and knowledge building around the child's heart defect. Anna described the current diagnosis of HLHS in her blog:

HLHS is for hypoplastic left heart syndrome for you who want to google. It means that the left ventricle of the heart is severely underdeveloped and cannot pump blood properly.

In her blog post, Anna explained her child's diagnosis and seemed therefore to have a good understanding of it, while she also suggested a keyword for readers who might want to read further upon this question.

Looking for medical descriptions online becomes relevant again for many parents once the child is born and during or close to the time of the heart surgery. Even though all parents in the study seemed to be satisfied with the information provided by the hospital staff, some reported a need to gain further control over the situation by finding as much information related to the treatment as possible. Christer talked about looking for information online while his new born son was being admitted in the intensive unit.

Christer: I felt that I needed [to google]. I don't think Tina needed it as much as I did but it can work differently. I needed it but I was nerdy. When he ended up in the intensive unit they connected him with a battery with those medicine pumps and there were, what can it have been, fifteen different preparations they gave him and on the displays you could see their names, so I wrote them down and went out and googled what it was. So, I was rather nerdy.

Christer described 'googling' for information as a 'nerdy' action. He seemed to have been aware that the information he found could not change his son's health condition. The situation described by Christer was therefore not primarily about filling in a knowledge gap. It was more about trying to gain control in a stressful and emotionally difficult situation. In this case, searching online lead to knowledge that was comforting and strengthening. This is an affordance with online searching that the majority of the parents in our study stresses as valuable.

Even at later stages, when the child is at home, consultation with medical staff can be complemented by information from the internet. The parents in the study often stressed the importance of knowing how to take care of their child after a heart surgery and seemed to rely upon the information found online. Gunilla wrote in her blog that she had used the internet to build up knowledge on Reyes Syndrome:

Most of all I was worried about Reyes Syndrome, about which I have written earlier. Reyes Syndrome is a disease that affects the brain and the liver and can be life threatening. Acetylsalicylic acid in combination with virus gives a higher risk for Reyes Syndrome and the syndrome attacks like lightning. Earlier today I had also, of course, googled that high fever can be a symptom of Reyes.

Gunilla had written about her child's current health condition before explaining what Reyes Syndrome was. She explicitly mentioned 'googling' when she explained symptoms of Reyes. Based on the information that she had read, she made the decision to immediately call the hospital. In her blog post, she passed on information on Reyes Syndrome for others to read. The possibility of quick access of information that would help parents know what was regarded as normal or divergent behaviour in the case of a sickness proved here to be another great affordance with online searching for medical information.

7. Looking for others' experiences

The second way of approaching the knowledge objects of heart defect and taking care of a child with a heart defect is by looking online for others' (usually parents'), experiences. In our study, we found many parents who had actively sought other parents' narratives and online interaction and found them helpful. A common reason that the participants gave for reading other parents' blogs and participating in forums right after having a foetal heart-defect diagnosis was in order to understand what life quality a child with a heart defect could have. In an interview, the couple Marcus and Rachel reflected on the story of a teenager they had met in an online group and compared his situation to a possible future life for their child. It seemed that this comparison helped them place their son's heart defect on a scale of severity.

Marcus: There was a boy who had graduated from high school, 18 years, he is one of the oldest I think

Rachel: He even got the highest grades in PE, that was to us

Marcus: Yes he is very active

Rachel: Because we were like, well our son will be standing in some corner not being able to move

Marcus: But in that group there are, well different, everyone has different experiences. I think right now when we read ours [the diagnosis of our foetus] it is, well, probably the mildest grade

Another mother, Mali, said that she had started reading blogs as soon as she received the diagnosis. She found Anna's blog and read all about Anna's pregnancy and experiences after birth. Mali explained that reading the blog and showing some of the posts to her partner helped them take the decision to carry their pregnancy to term. Mali wrote a thank you e-mail to Anna:

I just want to say thank you for your blog about Mark. It has helped us to make the decision to keep our son who has been diagnosed with HLHS. We got to know about it last week when I did an ultrasound in week 19. I will read your blog to prepare for the birth of our son. I wish our son will be healthy and lucky like Mark. Thank you from the bottom of my heart.

Mali told Anna about her own experiences and wrote that she would continue reading Anna's blog to 'prepare for the birth' of her son. In the following interview extract, Mali not only reflected on what specific information she got from reading about other parents' experiences, she also reflected on her reasons for wanting this information:

Mali: I have read that all parents are scared and worried when their children are there [during surgery] and they can't do anything but wait ten hours for a phone call from the doctor, if it went well or not [...]. I want to prepare myself to be able to receive the message when it comes.

Online searching as a health literacy practice seems to do more than providing knowledge; in this case Mali drew strength and comfort from texts like Anna's blog. Similarly, in her blog, Anna wrote that people found comfort in realising that they were not alone in their agony. This was confirmed by many participants in the study who talked about comfort and feelings of solidarity when discussing the reasons why they read about other parents' experiences. Some participants seemed to have turned to a national heart child association for information, support and contact with other parents. Engagement in the association can involve both digital events like reading information at the website and attending 'real life activities' e.g. meetings or summer camps. Other participants in the study joined a Facebook site that functioned as a closed group. Aydah explained that it was much easier for her to open her heart in the Facebook group than talking with her family and friends. This was because she felt there would be no judgment or feelings of pity amongst a group of people who shared similar experiences. In her blog, Elin praised an online discussion group:

I had a steady platform on the Internet [...] my life line. A group with amazing girls, girls from everywhere and nowhere, with different personalities and experiences but with big warm hearts always prepared to lend a listening ear or a shoulder to cry upon, to share the others' joy and encourage when someone needed extra pep talk.

Elin described how the meetings in the forum group functioned as supporting, comforting and strengthening. She used physical metaphors like 'lend a listening ear' and 'a shoulder to cry upon', when she described activities like sharing joy and encouraging each other. Meetings with other parents can take place both online and offline. The intertwining between online and

offline here was part of the complexity of providing care to a child with congenital illness and disabilities.

It became clear that reading about other people's emotions seemed to be at least equally important for some parents as reading about medical facts. Online searching provided parents with the possibility to explore other parents' emotions and had an influence on their own feelings and consequent actions. The role of emotions in health literacy seemed to be a central one. Parents' decisions and actions did not always rely on medical facts; references to their feelings were common and essential and seemed to influence, to a varying extent, their health literacy practices.

Searching for other parents' experiences online could also generate negative feelings.

Reading blogs and forums was experienced by some parents as disturbing, especially by those who happened to find too many negative narratives. Some parents also said that they had been discouraged from the medical staff to read blogs. Most parents admitted that they were cautious with reading blogs and forums and aware of the risks, as the information available could be in the best case irrelevant and in the worst case untrustworthy. In the following extract, Per reflects on online family forums:

But the problem as I see it with these sites, these family forums, is that I could go in and make an account in two seconds and write whatever I want and lie as much as I want [...] they are no trustworthy source.

Issues of reliability and trustworthiness seemed to pose a serious restriction when it came to building up knowledge online and are common amongst internet users (Hu and Sundar 2010). The vast abundance of information and the potential lack of sources can make it difficult for parents to know what is real and what is an exaggerated account of reality, what is a fact and what is an opinion. The very activity of looking for information becomes problematic, as parents have different ideas of what meaning can be given to the concept 'information'. For some parents, trustworthy information comes only from medical staff, whereas others find it easier to trust other parents who have similar experiences. The matter is further perplexed when parents become their own experts and participate in epistemic communities (Landqvist 2016) by building up medical knowledge, being active in forums or by blogging about heart defects (Bellander, Karlsson and Nikolaidou 2016). This brings facts and opinions even closer to each other and therefore more difficult to tell apart. Here we see traces of two perspectives on knowledge where the first one is based on concrete information anchored in everyday experiences and the second one is evidence-based and scientific. No matter which perspective parents seemed to adopt, it was difficult to tell these types of knowledge apart and the issue could only be discussed as a matter of debate and contestation.

8. Looking for practical information

The third path parents in our data followed when looking for online information related to their child's heart defect was by looking for concrete and practical information. At the early stages, between RUL and the consultation with the cardiologist or immediately after the consultation, some participants turned to the internet in order to make an informed decision whether to terminate their pregnancies or carry to term. Again, parents here look for both, content generated by other parents and sources from institutions like hospitals. In the following extract, Rachel tells about how information from the internet of a concrete and practical kind helped her to feel safe in her and her partner's decision:

Rachel: he read that there is an Astrid Lindgren's house [an activity house at the hospital area] and there is this what's it called the Ronald McDonald house, and they help and you can stay there and 'look things have gone well for them' so he read positive stuff.

In this extract, Rachel explains how she and her husband did not read only about how other parents experienced their child's heart surgery, but also how they got to know details about the process, in this case about accommodation during the time of surgery. Heart surgery means, for a lot of families, a movement away from home which can last for several weeks. Many of the participants in the study expressed how they wanted to know details about the surgery, descriptions of the process before, during and after and of the way other parents have experienced it. Rachel said that she read forum discussions on children with heart defects during her child's surgery. In the interview, she mentioned some of the typical questions that parents discussed in these: 'Well, how do you do this, can you breastfeed the child after the first surgery? what is tube-feeding? do you use an oxygen machine?' Moa discussed pregnancy insurance in her blog and wrote: 'I got the advice to sign as many pregnant insurances as possible from a mother on the internet who had lost her child'. Mali said that she had read on a blog about how to protect a child from RS-virus after surgery:

She wrote [in the blog], when we go to the grocery store we must always try to avoid RS virus, that is, we have to go in the morning so no one else is there and we need to keep the baby in the pram for protection, it was like in detail, how to handle, and, and it was, we didn't know before.

Practical information seemed to also contribute to the parents' emotional empowerment as it helped them build the knowledge they needed in order to carry themselves and their child through this difficult time. The parents in our data reported finding this kind of information mainly in forums and blogs. Some of them expressed disappointment in that this practical information was not offered from the medical care, or in that it came at a late stage. In the consultation with the cardiologist after RUL and at the check-ups every four to six weeks of the remaining pregnancy, the information from the medical staff seemed to focus on medical check up and preparing for birth and surgery. Additionally, questions were often raised after the consultation meetings and the parents felt that it was easier to go online than to contact the doctors. It can be therefore concluded that searching online for practical information, everything from treatment process to health insurance, seemed to be for the parents an invaluable support in their knowledge building process.

9. Building up knowledge on health as a digital health literacy practice

Most of the participants in the study talked or wrote about using the internet in order to make decisions and take actions in relation to the foetus's or child's heart defect. The parents visited medical websites, read blogs and participated in forums in order to find information on which they would base their decisions and actions. Looking for medical descriptions was motivated by a need to better understand the illness and its cause and to make informed decisions when pregnant and when taking care of their child. Reading about other people's experiences could also offer information about medical issues, but in social media information was filtered through the lens of the lay expert: the parent, who becomes an expert by virtue of having experiences (Prior 2003). The different form and sources of online information results because

the information was often valued differently by the participants in the study. There were those who argued that trustworthiness could only be found in evidence-based and scientific facts (see also Carlsson et al 2015b) and there were others who valued information from concrete everyday experiences and considered it trustworthy and worth reading. Our study shows that the digital platforms have contributed in bringing these kinds of information closer to each other, in the sense that we cannot longer talk about knowledge coming from medical staff only or from lay experts only.

Many participants in the study looked for online information in order to gain a feeling of control. They often reported feelings of fear, frustration and hopelessness. Using the internet as a source of information was for many a way to take matters into their own hands. Participants in the study explained that the medical information found online often made the heart defect more accessible and easier to understand. Here the practice of accessing information in medical consultations was often intertwined with the practice of looking for online health information. The parents in this study used their medical consultations as a starting point in their searches. Looking for medical information online changes, to a certain degree, the power relations between doctors and patients, as patients are able to control, evaluate and complement the information they receive from experts.

Reading about other parents' experiences gave to some of the participants emotional control, as they were able to prepare themselves for what was to come. Many participants expressed that parents of healthy children do not understand their constant fear for the child, whereas this kind of understanding and support could be found in parents who experience a similar situation. The internet, in this case, seems to help parents become members of a larger community, to feel that they belong in a group where their thoughts and feelings are confirmed and where they are not shown pity, indifference or even anger (Stommel and Koole 2010, Rains and Keating 2011, Pettigrew et al 2016). This practice involves participation in online discussion forums and closed groups in social networks like Facebook. The analysis also shows that online literacy events are extended in time and space and take a global character. Parents could communicate about heart defect with experts and lay experts all over the world, without always realising the digital distances they travelled when engaging in these health literacy practices. Digital health literacy enables global communication about health, which however sometimes feels more local and relevant to the parents than interacting with family and friends.

The practice of taking care of the child was talked about in blogs and some of the interviews. Some participants used the internet for practical tips on caregiving already during the pregnancy. Here, the internet was essential as a source of information since medical consultations seemed to be oriented towards medical questions. This practice became even more relevant when the child was born, as many parents in the study used the internet as a guidance book in caregiving, drawing information both from medical sites and social media.

The participants' health literacy practices seemed to lead to a rather fast learning. We saw, for example, that in the process of searching parents learned to evaluate information and to navigate between medical sites in order to find the kind of information that was relevant to their case. Many parents in our study seemed to have learned a lot about their child's heart defect and some chose to communicate medical knowledge and their experiences to others in blogs, forum threads and Facebook groups. This generated a new literacy practice, the one of passing on knowledge to others, for example by blogging. In different degrees and in different ways blogging involved creating and sharing knowledge. An example of this was Elin, a

mother who could not find a precise sketch of her daughter's heart defect on the internet and decided to draw her own picture based on the notes she found in the child's medical journey. The new picture was posted in her blog with a detailed explanation of the daughter's heart defect. Elin thus designed her own trajectory when reading digital texts (Kress 2003). She, as many other parents in our study, was not a passive receiver of information; rather, she actively navigated between the vast material found online and evaluated it. Furthermore, she alternated from the status of the reader to that of the writer and vice versa. This example illustrates that when engaging in digital health literacy practices, parents have the chance to draw on their own experiences and become active in creating and sharing new knowledge. The roles of producers and consumers of information are not always separable online and a lot of people in the study could not identify with only one of these roles.

A clear restriction when it comes to searching for information related to heart defect online seems to be that the online content is not always adequate, relevant or accessible. This is confirmed by studies in medical research with a similar focus on parents of children with heart defect. In these studies, parents also expressed their frustration with the current information websites, both Swedish and international, and the researchers suggest that health professionals should be more active in providing guidance in patients' online searching (Carlsson et al, 2015b and Carlsson et al, 2016). The parents in our study felt that the first consultation meetings with the cardiologist were not ideally placed in time in order for the information to be digested. Many of their questions came at later stages and this was one of the reasons why the internet was used as a main source of information.

We wish therefore to argue here that engagement in health literacy practices go hand in hand with information appropriation and knowledge construction in matters of health. Parents take an active role in their knowledge construction and design their learning path, as they navigate in the vast amount of information available online and make choices about what is relevant, trustworthy and read-worthy. In this way, parents who draw upon these practices become experts not only on their child's condition, but also on the macro-practice of 'doing digital health literacy'. At the same time, we have shown that the internet as a health information platform allows for everyone to show their expertise by means of blogging, participating in forums and social media. The parents in our study not only searched for facts in institutional websites, they also looked for other parents' experiences and advice. This was experienced by some parents as positive and liberating, whereas other parents found that online information became, in this way, more complex to decipher. Despite this, parents talked about a number of other affordances when looking for health information online, not least the feelings of safety and control they would gain, and showed that the practice tends to become an indispensable part of doing health literacy.

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