This is the published version of a paper published in *Learning, Culture and Social Interaction*.

Citation for the original published paper (version of record):


Access to the published version may require subscription.

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Health literacy as knowledge construction: Learning about health by expanding objects and crossing boundaries in networked activities

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ARTICLE INFO

Keywords:
Health literacy
Activity theory
Expert knowledge
Experiential knowledge
Medical consultations
Social media

ABSTRACT

In this paper we examine health literacy as a set of practices that unfold in networked activity systems. Focusing on the literacy practices of pregnant couples and parents of children with heart defect, we show that they participate in multiple activities with the object of constructing knowledge about the child's condition. The contexts for these activities are doctor-patient consultations and the parents' online searching and sharing. The study builds on ethnographic interviews, recorded medical consultations and collection of texts from online forums, blogs and social media. An analysis based on literacy practices and activity theory shows that these activities enable parents' learning, but they can also be restricting as to the mediating tools they provide and the rules that dictate the tools. Additionally, the object of learning about heart defect is not always clearly formulated and stable but it keeps alternating and expanding. As a result, the parents cross boundaries between activities with different mediating tools, rules and communities and thereby different possibilities for learning. We show that doing health literacy is comprised by a set of recontextualised practices of looking for medical and experiential knowledge and it is by a combination of the two that meaningful learning is achieved.

1. Introduction

Looking for information, negotiating and learning about health is a common practice in a large part of the world. Most people have, at some point or another, been in the position of having to process medical information, evaluate it and use it to make critical decisions about their own or a relative's health. Engaging in health literacy practices is relatively easy but also relatively complex when done in the context of an information society, where information about health is abundant and individuals are expected to know how to access it and use it in order to take responsibility for their health. Knowledge on health and illness is negotiated in a number of activities that take place in institutional settings like hospitals, as well as in informal online patient associations (Rains & Keating, 2011; Stommel & Lamerichs, 2014; Sundar, Hatfield Edwards, Hu, & Stavrositu, 2007). With the internet giving access to all sorts of sources for medical information, learning about health online has spectacularly increased in popularity. The internet is an unquestionably dominant source of information both for medical and experiential knowledge. Medical knowledge is traditionally constructed in the interaction with medical experts and an easier and wider access to medical knowledge is made possible through the use of medical websites. Patients can read medical information online but they can also interact with experts, get answers to

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https://doi.org/10.1016/j.lcsi.2018.11.003
Received 28 June 2018; Received in revised form 6 September 2018; Accepted 20 November 2018
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Learning about health requires a constant boundary-crossing between activities in order to put together the pieces of one's health in a variety of distinctive yet complementary contexts. We approach these contexts as a network of activity systems and show that they alternate between looking for medical and experiential knowledge in a labyrinth of health-related knowledge and show how they undergo transformations. Wider access to knowledge as well as trends and policy shifts have brought about a larger patient involvement in medical consultations (Collins, Britten, & Ruusuvuori, 2007). Expectations that patients have to unquestioningly comply with doctors’ instructions have, in the last decades, been replaced by models where medical consultations to a larger extent are seen as exercises in shared decision-making (Lupton, 2003). At the same time, patients negotiate knowledge about health outside clinical settings, in their interactions with family, friends and other interested individuals who may or may not share similar experiences. Learning, negotiating and acting upon one's health are all actions in the complex landscape of doing health literacy.

In this paper, we want to examine the practices of doing health literacy as they are being enacted in diverse contexts and a large number of human activities. We do this by examining how parents of children with a heart defect go about in order to make meaning of their child's heart defect diagnosis, process it, take control and cope with it in their daily life. We follow the parents' journey in the labyrinth of health-related knowledge and show how they alternate between looking for medical and experiential knowledge in a variety of distinctive yet complementary contexts. We approach these contexts as a network of activity systems and we show that learning about health requires a constant boundary-crossing between such activities in order to put together the pieces of one’s health puzzle. The research questions we seek to answer are the following:

1. What kind of knowledge is accessed in the activity systems in which parents participate when engaging with health literacy?
2. Which mediating means enable or restrict learning in these activities?
3. How do new needs for learning develop and lead to boundary crossing between activities?

The case study discussed here builds on data from the Swedish linguistic research project Health literacy and Knowledge Formation in the Information Society. The project concerns pregnant couples and parents dealing with a diagnosis of heart defect in their fetus or child. The data consists of ethnographic interviews with parents and cardiologists, recorded medical consultations, medical web-pages, patient blogs, Facebook and Instagram posts. We argue that it is only through a wide variety of data that includes recordings from authentic events, a rich collection of health literacy texts and interviews with a focus on events and emotions that we can understand the process, meaning and implications of doing health literacy.

We use the conceptual framework of Activity Theory (AT), as a descriptive and orientational framework in order to show the variety of contexts and activities in mediating health knowledge in the information society. AT helps us place the pursuit of knowledge at a central place in our participants’ activities and examine what happens when knowledge takes different forms that can be accessed when moving between contexts and when participating in a network of activities. An additional aim with this study is to discuss how we can examine learning in activity systems when the participants’ objects are not clearly formulated or when they keep changing as new needs develop in the process of one’s health journey. We approach learning about health and illness as an expansive process (Engeström, 2001), a kind of learning that is not top-down and restricted in one activity, but a process that can also be horizontal and take place at the interplay of networked activities. We argue that health literacy is mediated by access to expert and experiential knowledge constructed in parallel and interacting activities, such as oral interactions with medical staff, medical websites and social media. Different activities enable different kinds of knowledge and restrict others and health literacy practices are experienced as meaningful when crossing between activities and recontextualising knowledge.

2. Earlier research on doing health literacy

Crossing boundaries between activity systems in order to build up knowledge about health is discussed as the broader practice of doing health literacy. The study of literacy here builds on the view of reading and writing as situated practices that are only turned meaningful in the context they are being enacted (Barton & Hamilton, 2012; Street, 1984). Within this theoretical framework we understand health literacy as knowledge building and meaning-making processes, performed as social activities situated in time and in place (Dray & Papen, 2004). Learning about one's health is not viewed as a skill that one can master in a way that is more or less successful or correct and that is directly connected to health outcomes. Instead learning about health is understood as complex cognitive, social, cultural and affective challenges.

Textual mediation is an important concept in the study of health literacy. Medical institutions use texts as a way to communicate information to large audiences and patients use texts in order to make sense of their health, but these are not always unproblematic practices. Hunter and Franken’s (2012) study of health information documents in New Zealand showed that information can be presented in a complex and potentially excluding language and form. Not understanding health information can be the cause of embarrassment and lead to silenced questions and non-taken actions. Similarly, Dray and Papen (2004) discuss information in health leaflets as potentially contradictory to the patient’s own experience and therefore discarded as confusing or irrelevant. It is often the...
case that patients need to find their own ways in health literacy, by finding sources that they assess as relevant or by using other learning methods, e.g. their social networks. In yet another study, Papen (2008) examines her own literacy practices during her pregnancy and points to the significance of reading and writing in the cultural and social framings of pregnancy.

The challenges of health literacy become even more complex in the context of neoliberal governance (Fairclough, 2000) where individuals are held responsible, amongst others, for their own health and for their own learning. An important aspect in health literacy is the ability to find and critically interpret information, understand diagnosis and participate in decisions about treatment. This is particularly important for parents who engage in health literacy practices in their role as caretakers of a child. In a study of the communication of health knowledge amongst new parents in Sweden, Hanell (2017) shows that the responsibility for health knowledge is felt as particularly heavy amongst parents and that difficulties with taking health decisions are often experienced as failure in one's parental skills. Similarly, Papen (2013) shows that pregnant women engage in a large number of information searching practices, while continuously having to assess content and sources. In one of our earlier studies (Bellander & Nikolaidou, 2017), we examined the practices of doing digital health literacy when being pregnant or a parent of a child with heart defect and we showed that some of the common practices when doing health literacy online is browsing medical websites and participating in social media, due to a need to understand how medical facts and other parents' experiences can be related to each other. We argued that taking an active role in knowledge construction by designing one's own learning path is a common characteristic of digital health literacy.

Reading and writing texts is an unquestionable part of doing health literacy. The same can be argued about the role of oral interaction. Negotiating about symptoms, diagnosis and treatment, cross-checking information, describing one's health condition, these are all practices that require people to engage in complex conversations and sometimes show advanced argumentation and/or interpretation skills in order to successfully participate in them. Approaching literacy as a situated practice requires us therefore to lift our gaze from text use as an isolated practice and examine their role in wider communicative situations and how text and oral exchanges together shape a literacy practice (see Harrington & Valerio, 2013).

Learning about health is understood as a unique journey for each individual, depending on factors such as the way one's health develops, one's need for control, for support and for empathy, one's social networks, personal history, educational background and other factors that play a decisive role on what and how much a person wants to know about their health and what they want to do with this knowledge. It is the actions taken when learning about health together with the generated attitudes and feelings that we refer to as the practice of doing health literacy in this paper. It is a concept that encompasses the total of literacy practices that an individual engages in when being on a health journey Building up knowledge seems to be an indispensable part of doing health literacy if an individual is to take informed health decisions.

3. Data and methods

3.1. Data collection

In order to understand the way the parents in this study build up knowledge about health by means of reading, writing and negotiating information orally and in text, we collected rich ethnographic data, audio recordings and texts during a three year period; 2013–2016. In this paper, we specifically draw on data collected by means of interviews with parents and cardiologists, recordings from medical consultations, extracts from patient forums and postings on parent blogs, Facebook and Instagram.

The project is not longitudinal in the sense that the same parents are studied through their health literacy journey. Instead a great number of participants help out forming the large picture of health literacy practices in the process of dealing with children's heart defects. Some thirty parents participate in more than one dataset, for instance in a recorded medical consultation and in an interview, or as blog author and as author of Instagram posts.

The project database consists of 25 recorded and transcribed in-depth interviews with pregnant couples and parents. The interviews with the parents are performed in different stages of their pregnancy and parenthood. Some were interviewed right after they had received the diagnoses, in pregnancy week 18–19, some closely after birth and initial surgeries. We have also met parents of children whose medical treatments have been considered completed and couples who have decided to terminate their pregnancy. In the interviews, we asked the parents to give us a detailed narrative of their experience. Our follow-up questions focused on their information seeking practices during the different stages of pregnancy and parenthood and on their learning. For example, we asked parents to give us an account of their consultation meetings with the cardiologists, with an emphasis on what they believed they had learned, what was difficult to understand and what more they would have liked to know. In interviews with parents who blogged we asked the parents to reflect on the aims and on the content of their blog, as well as on the process of writing.

We have observed and recorded 19 consultation sessions between cardiologists and pregnant couples. In eight of these the parents meet the cardiologist for the first time. These eight initial sessions are included in the analysis of this article. The sessions vary between 15 and 60 min, with the presence of the parents, a cardiologist and, in six out of the eight sessions, a specialised nurse. Three different cardiologists are participating in the eight meetings. We have also conducted a group interview with the three cardiologists with a focus on communication during this first consultation. Parent blogs and family forums are another large piece of the project data, in total 14 parent blogs and 18 discussion threads from online family forums. The forum interactions are threads found in two popular Swedish family forums and were accessed by googling the keywords Heartchild (hjärtebarn) and Forum. The parent blogs were selected based on the criteria that the blogger is a parent of a heart child and that the content of the blog is partly, but not exclusively, related to the child's heart defect. We have access to two of the blogging parents' Facebook accounts and we follow the hashtag #hjärtebarn (#heartchild), on Instagram. In the moment of writing (fall 2018) it consists of 11,791 postings. We have left out or changed the names of people and places in the data excerpts included here.
3.2. Coding of the data

We have used the software Atlas.ti (see Paulus & Lester, 2015) to code our data. As a descriptive and orientational framework for the coding, we have used the conceptual frameworks of literacy theory and activity theory. We identified occurring literacy events and coded them further with a focus on literacy artefacts, reasons for engaging in the events, attitudes and emotions related to literacy. We have also coded the aspects of time and space in relation to these events. At the second stage of coding, we coded the identified literacy events using the elements of an activity triangle as codes, with the aim to place them in larger activity systems. The first consultation meeting with the cardiologists is discussed by parents and doctors in our data as a very distinct activity. The parents' identified literacy events using the elementsofanactivitytriangleascodes,withtheaimtoplacetheminlargeractivitysystems. We have therefore identified three different large activities in which the parents participate when doing health literacy online: looking for medical knowledge, looking for experiential knowledge and sharing ‘knowledge. Using a set of codes that combines concepts from literacy theory and activity theory allowed us to see that literacy artefacts, literacy events and the broader literacy practices related to them often extended the limits of one activity system. They were instead taking new forms as they were recontextualised from one activity to another.

3.3. Activity theory as an analytical framework

Activity Theory is a contextual theory that describes human actions as parts of purposeful activities of a collective nature that involve learning. Activities are constructed as a result of people’s biological and psychological needs that lead to the creation of motives (Leontiev, 1981). The “true motive” of an activity (Leontiev, 1978) is its object and focus is given on the mediated action that is a necessary step in order for subjects to achieve the object of the activity. In the most recently developed and now most widely-used version of AT, the mediated action of the subject is completed with contextual factors, the community, the rules that shape the system and the division of labour between the participants (Engeström, 1987; Kaptelinin, 2014). AT has mainly been used to study institutionalised activities, not least in healthcare contexts in relation to, amongst others, diagnosis (Engeström, 2000), patient experience (Cornet, Voida, & Holden, 2018; Kerosuo, 2006), information systems (Mursu, Luukkonen, Pentikäinen, & Korpela, 2007), documentation practices (Nikolaidou & Karlsson, 2012) and administration (Engeström, 2001). In this article the use of AT is broadened to look at a wider practice, the practice of engaging in health literacy. The object-oriented nature of activity systems helps us place learning at the heart of doing health literacy. Learning about health seems to be the main outcome that people who engage in health-oriented activities want to achieve, i.e. the activity’s motive. Some more specific objects can be to understand a diagnosis, to calculate risks, to take decisions, to share opinions and emotions and to document experiences. An analysis of our data within the AT framework also enables us to show that learning about health is constructed as a collective process. The parents are not alone in their quest for health-related knowledge, but they are surrounded by a number of people – medical experts, experiential experts and non-experts – who discursively co-construct knowledge about child heart defect with them. In AT the collective aspect of learning takes the form of the activity’s community, described as “a complex and relatively enduring community of practice” (Engeström et al. 1995: 320). It is a community of practice where the subjects not only share common interests and practices (Wenger, 1998), but more importantly they share a common object. Division of labour is also an important concept in the analysis as different kinds of expertise give the members of the community different roles and tasks in the activity. An activity system is underpinned by rules that dictate what actions can and cannot be taken and in which way they should be taken. This is also an important factor to consider in the study of health literacy, as rules are particularly important in institutionalised contexts like hospitals, but also in online contexts like family forums.

The abundance of information that came with the internet created new needs and desires in people’s activities. In AT, biological and psychological needs are described as the ultimate cause behind human activities (Leontiev 1978, Kaptelinin & Nardi 2006:60). The appearance of new needs leads to contradictions in the system and possibly to the system’s expansion. An AT analysis enables us to place this dramatic change in the way people do health literacy in context and show connections but also contradictions between traditional mediational means, such as doctor-patient interaction and new mediational means, such as digital information and interaction. To this end, we will show how connections and contradictions lead to the systems’ expansion and motivate people to move between multiple activities in order to learn about health.

Finally, an AT approach in the analysis allows us to approach health literacy as a broad object of human activity. It is an object that cannot easily be pinned down to concrete contexts and that keeps taking new forms even in the same activities. Additionally, health literacy is seen as an object that involves a large number of subjects from multiple networked activities and is approached from various perspectives: a professional, a societal and an individual. Such large-scale foci of human activity have been described by Engeström (2006) as “runaway objects” and call for analytical tools and methods that are rich and diverse. At the same time, the researcher needs to be prepared never to fully be able to capture the complexity that underpins the activities involved in pursuing runaway objects and the many ways that they are connected and shape each other.

4. Results

Learning about heart defect and about living with the condition was mainly achieved in two distinct but parallel and interconnected contexts in our data: the medical consultations that take place in clinical settings and the parents’ online activities when looking for further information. In this section, we will look closer at the activities enacted in these contexts and examine how they
are connected or, in other words, how subjects are motivated to cross boundaries between them in order to construct knowledge about health. The activities have a common motive, the pursuit of learning about health and they therefore permeate each other, without always knowing where one ends and the next one starts. Such analytical difficulties are telling of the complexity inherent in health literacy practices.

The medical consultation could be seen as a typical activity system, a set of mediated human actions that can easily be traced or observed with a clear object, rules and roles. This is however not really the case as the activity's object is, in this case, neither clearly formulated nor the same for all participants. The parents' online practices are part of an also complex set of networked activities: looking for medical knowledge, looking for experiential knowledge and sharing knowledge. The parents' online activities are not easily observable systems and it is therefore more difficult, from an analytical point of view, to reconstruct them.

4.1. Learning in medical consultations

Consulting a medical expert is, for many patients, the first big step in their health journey. In order to examine learning in medical consultations we draw on examples from a specific encounter in our data, namely the first time when the pregnant couples meet with a child cardiologist after the suspected heart defect has been discovered. From interviews and blog posts we know that many couples consider this meeting to be crucial, as a departure point of their health journey.

The fact that the patient, i.e. the child, is not yet born makes this consultation different from most other visits to a clinic. In our interviews with the pregnant couples many report that they had no idea what to expect, whereas others were prepared to various degrees not least by means of online searching. From their perspective the object of the activity is, at this point, rather vague. They want to find out if there is a diagnosis but they are new to this activity and they do not know what to expect or what is expected of them. The medical experts, on the other hand, are experienced members of this activity and they have a rather concrete object formulated: to consult, to explain the diagnosis, prognosis and possible treatment. This is however not a simple object to achieve. Since the fetus is small and in many cases vivacious, it can be difficult to interpret the ultrasound pictures and give a correct and understandable diagnosis. In excerpt 1 that comes from the beginning of a consultation session, the cardiologist gives a description of the activity's object the way they see it.

(1)

Doctor: Our task now is to give as much information as we can about the condition and what it means and what it means in terms of treatment what options are available what predictions and what it is like to to live with [the condition].

In the consultation the main mediating tool used to communicate knowledge to the parents is oral interaction. The doctor engages in a rather lengthy session describing the anatomical details of the fetus's heart, comparing it to a healthy heart and explaining the treatment. Looking at the division of labour, we see that the interaction is often rather monological as the doctor goes into long anatomical explanations of treatment and prevalence. The pregnant couple participates mostly by nods and short comments, as will be further illustrated in excerpt 2. Medical knowledge is rather transferred from the doctor to the pregnant couple than co-constructed between them. This is, to a large extent, due to the nature of the diagnosis where the pregnant woman is not able to participate by sharing her experiences and the diagnosis is made possible only by the ultrasound scan.

In line with the activity's rules, the information provided during the consultation is evidence-based and either anatomical or related to earlier cases and statistics. A contradiction often takes place here between the doctors' object of informing about the diagnoses and the parents' object of understanding the information. In our interviews, many parents explain that during this first consultation meeting they were overwhelmed with emotions to the degree that the information was too much or too complex to digest. The medical staff seem to acknowledge this and partly address this contradiction by employing visual aids as a new mediating tool that will help make their medical knowledge more accessible. The visual aids take the form of heart sketches, which they draw in order to illustrate the heart's malfunction. Besides illustrating the monological structure of the consultation talk, excerpt 2 shows the doctor's use of sketching along with oral interaction. The plain and clear heart sketches mediate the information taken from the ultrasound pictures by translating it to a more accessible for the parents' language.

(2)

Doctor: it is like this, I see two outflows but it is a bit different here, I am drawing the heart, the heart is pumping, it is functioning well in there now
Pregnant: mm
Doctor: and then we have two nice chambers here like this ((sound from pen against paper)) there is no difference, they are good both chambers, when it comes to how the vessel leaves from the heart I can see that this here is broken, this line here that I talked about
Partner: mm
Doctor: it should be here by the big body pulses, it should only go down that way, that's how it should be if normal
Pregnant: mm
Doctor: then I remove the rest but here this line here that line
Pregnant: yes

In interviews, many of the parents described the sketches as a good memory aid when being alone at home processing the information from the doctor. The sketches are therefore a mediating tool that stretches over time and space and is used in new activities with a similar object.
Even though the interaction has been described as rather monological, multivoicedness is still permeating the activity. The doctor's descriptions and explanations generate questions and slowly re-shape the parents' object, which is now becoming more concrete and negotiable. They do not only want a diagnosis. They also need information on how to deal with it. Their needs of learning change and this becomes clear if we look closer at the questions they ask. Many parents seem interested in the child's future physical and cognitive abilities, for example abilities to perform in school and in sport activities. To meet these questions the medical staff often draw on statistics and make comparisons with general cases. When the doctors guide the parents through practicalities around the birth and the heart surgeries the parents often ask questions about the time and place of the birth. The parents' questions are most often met with adequate answers. However, it can sometimes be the case that their questions exceed the limits of the activity, when they are not in line with the activity's rules about what one can and cannot ask in this context. For example, some parents press for more concrete advice as to whether they should carry the pregnancy to term or terminate it. In such cases, the medical staff are restricted by the activity's institutionalised rules that require them to remain neutral in their advice. Excerpt 3 shows how one such question from the partner to a pregnant woman is met by a doctor:

(3) Partner: what do you think, what is the best so to speak?
Doctor: well we, we or I, I can't have an opinion about that really, this is ... we deal with this pretty often and it's so different

Excerpt 3 shows that multivoicedness leads to the expansion of the object. The pregnant couple now wants very specific advice in relation to the pregnancy that contradicts the doctor's object to explain and consult within the limits of expert neutrality. This contradiction leads some of the parents to enter new, non-institutionalised activities such as the online communities, where they can hopefully set their own agenda and interact with others on equal terms. Additionally, this contradiction leads to the activity's expansion: the medical experts cross the activity's boundaries and support the couples' learning activities outside the consultation room by writing down keywords to use when searching online and giving them links to trustworthy websites. In excerpt 4 a doctor gives instructions for online searching:

(4) Doctor: There is a name for this, a diagnosis, so you can search for this and start reading about this afterwards. It is called Fallot's anomaly, it was an old man called Fallot's who was the first one to describe this and for Fallot's anomaly in English you have to use an apostrophe, much is in English, writing the surname will be enough

This action opens up to the parents' participation in other learning activity systems; the doctors support the parents in their need to process and deepen their knowledge and understanding of the diagnosis and urge them to recontextualise the facts in a critical and informed way. The contradiction is here balanced by the doctors by means of providing the parents with new mediating tools that open the door to new learning activities. These mediated tools also make it possible for parents to recontextualise knowledge between activities. In the next section we will show how knowledge is transferred from the consultation to the online activities. However, the opposite is also possible and rather frequent. In doctor appointments later in the pregnancy, it is common that parents bring with them information accessed online, followed by the request to negotiate and evaluate it. In these cases, online accessed information becomes a recontextualised mediating tool that crosses the boundaries and enters the medical consultation activity. Excerpt 5 is from a medical consultation that takes place a month after the couple's first meeting with the specialist.

(5) Mother: you can read so much, and I got worried about lack of oxygen to the brain when you disconnect the aorta
Doctor: right
Mother: and lack of oxygen, you can be paralysed, I read on the internet a little here and there, but it turned out it was not an actual problem
Doctor: exactly so it worried you for no reason

In this example, the mother used the internet to find more information on heart surgery. The information she found online raised new concerns and her way of dealing with her anxiety was to bring the new knowledge back to the medical expert for cross-checking. It is likely that not all medical professionals respond positively to this initiative, as it can be received as a rather threatening attempt towards their own expertise (e.g. Hart, Henwood, & Wyatt, 2004; McMullan, 2006). In our data, the cardiologists seem to acknowledge the role that online information plays in parents' learning and collaborate with them in order to analyse the introduced information. At the same time, the doctors often claim to have the best knowledge to offer the parents, since they understand the child's specific heart defect. The parents recontextualise medical knowledge from one activity to another but leave the affective and the experiential sides of knowledge outside the medical consultations. We have, for example, no examples where the parents consult the doctors about online information related to the emotions experienced when being a parent to a heart child.

The medical consultation as a learning activity seems to function for the parents as a first platform in a longer learning process. The parents' learning needs as an object for participating in the activity keep taking new forms and this is a double challenge for them: first because they do not have a strategy as to what questions to ask in order to get the right answers and they make these up along the way, and second because they need to constantly negotiate with the medical experts what kind of knowledge is available for them in this activity. Medical knowledge seems to be generously provided to them but when it comes to advising of a more subjective nature they need to look for another kind of knowledge or for settings with different rules and for this they have to cross boundaries and enter new activities.
4.2. Learning in online activities

In this section, we follow the parents’ search for knowledge on heart defect in a new series of networked activity systems, the ones mediated by digital tools. As earlier stated, it is an analytical trap to try and keep people’s online activities separate. This is because searching for information and knowledge online is rarely a set of activities with clear-cut time and space boundaries. People tend to work with parallel tasks when being online and the same seems to be true for engaging with digital health literacy (Massin, Montesanti, & Gerard, 2006). The interviews we have conducted with the parents and a systematic coding of the literacy events described in these have helped us to this end. In many of the interviews the focus of the discussion seemed to be around information sources, whether it was coming from medical experts or from other parents with similar experiences. This was a dilemma that concerned many of the participants in our study and they often talked about doing different things when looking for knowledge from medical experts, when looking for knowledge from other parents with similar experiences and when sharing their own knowledge. We came therefore to see these as distinct objects that define three different activities: looking for expert knowledge, looking for experiential knowledge and sharing knowledge.

4.2.1. Looking for expert knowledge

The most common reasons mentioned in our interviews for engaging in the activity of looking online for expert knowledge on congenital heart defects is to confirm the diagnoses or gather additional information after the first consultation meeting with the cardiologist. The object of this activity varies for different individuals but some of the strongest ones are to process the diagnosis, to find complementary information and to cross-check facts about diagnosis, prognosis and treatment. The medical websites provided by the cardiologists during the medical consultation are commonly used mediating tools. Terms for diagnosis and treatment re-contextualised from the consultation function also as mediating tools, used as keywords in search engines in order to find relevant knowledge. Some parents mentioned the use of keywords in English or in other languages as a strategy for accessing more websites.

The rules for participating in the activity are rather straightforward: the online medical information is available for anyone to access and the information seeker can go back to it as many times as s/he wants. The implicit rules, however, can dictate some prior knowledge of medical jargon in order to be able to decipher the information. This is because the division of labour of this activity is structured in such a way that turns the medical experts to providers and the parents to receivers of knowledge, often excluding any form of interaction or co-construction of knowledge. Similar to the consultation activity, the texts are monologic and the experts’ voice is dominant. There is, in other words, a contradiction here between the tools and the object of the activity: looking for medical information online in order to learn more about health issues cannot be easily accomplished if the information is complicated and if there is no expert mediating the medical knowledge. A frequently used tool mediating between parents and these complex texts are pictures and anatomical illustrations of the heart that potentially help parents visualise the medical descriptions. Fig. 1 shows information on children’s heart defects on the Swedish national website 1177 Vårdguiden. The picture to the left is the start menu for the theme congenital heart defects. The main heading reads “Congenital heart defects in children” and the three following headings read “Summary”, “General facts” and “Symptoms”. The picture to the right is found further down on the webpage and shows a written and illustrated description on heart surgery with the method shunting.

Due to the lack of direct physical or verbal contact with experts in this activity, there is an extra difficulty of needing to continuously evaluate the information and make decisions of what to keep as relevant and trustworthy and what to discard and this task requires some prior knowledge on the subject. Accessing health information that is trustworthy is a common concern amongst internet users (Carlsson, Bergman, Melander Marttala, Wadensten, & Mattsson, 2015; Eysenbach & Köhler, 2002) and the interviewed parents in our study expressed the same fears. This can be seen in excerpt 6 where a couple resonates that trustworthy online information can only be provided by medical experts:

(6) Mother: if you look for information about anything that has to do with children then you think more about which websites, because 1177 [the Swedish national website] for example that one, it is a bit easier to trust that one […] but what if there was a
website where you could read that a surgeon
Partner: yes one where you could ask a question to a specific cardiologist

However, online information about medical facts is not only generated by medically-trained experts; experiential experts (e.g. other parents or patients) can also create similar medical descriptions and share them online. The wider sense of community offered by the internet can function here as a contradiction, as many of the parents want to access trustworthy information provided exclusively by medical experts and they need to constantly evaluate their sources. Finding relevant information is yet another contradiction. The abundance of available medical information and the parents' lack of medical expertise can make it difficult for them to decide what is relevant for their child's diagnosis.

Despite these contradictions, engagement in the activity of looking for online medical facts offers many learning opportunities. More importantly, the widely available nature of the mediated information and the fact that it can be accessed without any time or space restrictions makes it a particularly popular activity when doing health literacy. An additional affordance is the size of the medical community that can be reached in this activity; the parents in our study get access to medical facts and other experts' opinions all over the world and have the possibility to cross-check and compare. This is a unique mediating tool for learning and probably the reason why digital health literacy has taken such enormous dimensions in the information society.

The fact that it is again doctors mediating knowledge offers other possibilities for learning: the parents can compare and confirm the expert advice. The time aspect is important, as the parents have a clearer idea, by this time, about what they need to learn, and they better understand what kind of information they should look for. The doctors mediating the information in online websites are not acting in the same institutional context as in the hospital and the rules are not so strict. The information therefore provided can be more congruent with the parents' need for knowledge. It is the parents setting the agenda here, they choose what questions they can ask and how much time they need for processing the information. The experts mediate between parents and their object to obtain knowledge but they do it from a safe distance and partly on the parents' conditions.

4.2.2. Looking for experiential knowledge

An equally large activity when engaging in digital health literacy practices is looking for experiential knowledge online. In this activity, the main object is to construct knowledge together with people who have had similar experiences. Many of the interviewed parents in our study talk about the need to leave statistics behind and read about real people and their everyday struggles when living with heart defect. Construction of experiential knowledge mediated by other parents often comes hand in hand with participation in online communities, where one cannot only find but also request and share information.

Social media is an important mediating tool in this activity. The parents in our study make use of all kinds of available channels, such as blogs, forum threads, Instagram and Facebook groups in order to read and participate in discussions about their child's heart defect. Experiential knowledge in social media enables the parents to understand how it is to give birth and live with a child with heart defect. This knowledge is most frequently structured with the help of narratives as mediating tools. Through narratives parents account for the child's health journey chronologically, sometimes over the period of days as in excerpt 7 from an Instagram update marked with the hashtag #hjäretbarn (#hearthchild):

(7)
Look what a warrior she is this girl! The last days Emma has been struggling with nausea and today I suspect that she is catching a cold again...??
The doctor has decided to do a new x-ray to see that her intestines are okay after surgery. I think that is good news since Emma has felt worse and hasn't been able to eat much since her surgery last week.

On blogs and other social media, narratives are used in combination with photos. For example, seeing pictures of children right after a heart surgery seems to be important for many parents who expressed in interviews that they want to get mentally prepared for the future.

Another form that experiential knowledge can take is that of learning about practical details. Many parents want insiders' information in relation to being a patient (or the parent of a patient), e.g. giving birth and undergoing a heart surgery. To this end being active in family forums enables them to get answers to many questions, from an evaluation of the staff in a certain birth clinic to feeding techniques and dilemmas about nursery schools. There is a large degree of freedom in relation to the topics discussed and the questions asked in social media. The parent communities are mostly built on the premises of openness and support. As a result of this, experiential knowledge is often expressed with a strong dose of reference to emotions; the parents who read the shared posts and comments learn how it feels for someone else to be a parent of a child with a heart defect. Excerpt 8 from a Facebook update shows how this kind of knowledge is usually worded and structured:

(8)
Sometimes I get so bloody sad when I think of everything we've missed and everything we've been through. Not having you on my chest, not being able to hold you, look at you or be with you for SEVENTEEN hours. Sometimes reality gets to me & I just get so sad.

Some of the interviewed couples argued that reading posts similar to the one in excerpt 8 was particularly useful, as it enabled them visualise and prepare for the emotional pressure that they were likely to experience later on.

The activity's community functions in this case as enabling but, sometimes, also as restricting knowledge construction. The relative homogeneity of the community's participants can result in limited access to new, general and comprehensive medical
knowledge and can lead to misunderstandings. The contradiction here does not have to do with evaluating whether the information is trustworthy, but with estimating its relevance for one's own case. Heart defect can take many different forms as very few cases are identical, and a parent needs to be careful with comparisons and overgeneralisations.

Some of the positive outcomes from reading and taking part of other people's experiential knowledge is that parents get access to information they are looking for but also information and knowledge that they did not know they needed but which proves to be useful. At the same time, they become members of a community. They create a contact network which is useful to them not only for the knowledge it provides but also for the emotional support they find in it. Reading other people's narratives gives a parent or a pregnant couple not only access to facts but also to an idea of what it feels like to have a child with heart defect or to terminate a pregnancy. This is a kind of knowledge that is unique in this activity as it is mediated by a large community with members who have all gone through similar situations. Learning about heart defect is thus expanded to include not only medical facts but also learning about others' stories, thoughts and feelings and relating them to one's own current situation.

Looking for experiential knowledge is a complicated activity with a diverse and thus difficult to pin down context. Baillergeau and Duyvendak (2016: 416) identify eight potential features or areas where experiential knowledge is used as a resource and as many as six of them can be traced in our data: the experience of having been through a condition, the experience of handling multiple and concurrent difficulties, the experience of having lived through care institutions and treatment, the experience of social sequences of a condition, the experience of discovering coping strategies and the experience of recovery. These are common themes mediated by online communities that contribute to the parents' desired object of learning about heart defect and living with a child with this condition. Many of the parents do not restrict themselves in the activity of taking part of this knowledge from other community members, but want to contribute to the distribution of knowledge by sharing similar context. Reading and sharing experiential knowledge are two sides of the same coin in health literacy and the activity of sharing will therefore be further examined in the following section.

4.2.3. Sharing knowledge

Sharing knowledge online is an activity intertwined with the activity of looking for knowledge. The parents act as subjects in two networked activities that unfold in close relation to each other. The limits are blurry as the common motive of learning is still dominant, but there are different immediate objects and partly different mediating means related to each one of them. The following entry in a family forum shows how the two activities are interconnected in time and space:

(9)

Hi! I’m new here. On Sunday 2/2-12 our daughter Mary was born with a heart defect -Fallot’s anomaly. We were of course very worried immediately and I especially have cried ever since then, It's difficult to be happy, even if it sometimes feels as everything is normal and that there is nothing wrong with her.

My first feeling was that she will disappear from me, that she will not survive. [...] How did you handle the time before the surgery? Have you initiated contact with others in the same situation?

This parent shares her story at the same time as she calls other forum participants to share theirs and give her advice. She is thus both sharing and looking for experiential knowledge and it is therefore difficult to place her action in a concrete spatial and chronological context.

The dominant social media used by the interviewed participants in the study are Facebook and Instagram but blogging and participating in family forums are also common ways of sharing experiential knowledge. The new aspect in this activity is the introduction of writing and sharing narratives (rather than only reading them or prompting them by means of asking questions). Other common mediating tools are photography, reference to other sources and citations.

Sharing experiential knowledge when doing health literacy usually involves narrating events of everyday life when being pregnant or taking care of a child with a heart defect. This can include hospital visits, value saturation measurements or tube-feedings, but it can also include visits from grandparents, engagement with charity organisations and emotional breakdowns. The posts do not address a medical epistemic community but a social community of relatives, friends and known and unknown parents of other children with heart defects. These texts become meaningful when studied as part of the parents’ contextualised, purposeful activities.

Our interviews with parents suggest that the object of sharing experiences, thoughts and emotions is usually comprised by actions with rather complex and often multiple goals. Processing negatively loaded experiences by writing about them is a common aim with sharing experiential knowledge. Dealing with strong emotions by putting words to them and externalising them are examples of the kind of processing that takes place when sharing experiences digitally. Apart from these inner goals that aim to fulfil individual needs, sharing is also established as a social activity that intimately relates writers and readers (see Nardi, Schiano, & Gumbrecht, 2004 on blogging). A common goal that drives the activity of blogging as a social practice is to keep contact with family and friends and to reach out to other interested readers. Digitally documenting events contributes to creating and maintaining a strong community in the activity. Helping others in a similar situation is also a way that the parents hope to give something back to the community. A final goal in the sharing activity is writing as a memory aid for the future. Sharing knowledge becomes, in this way, a mediating tool related not only to this health-related activity system, but to the wider activity of parenthood.

The rules in the activity of sharing knowledge can vary depending on which social media platform is used. Different platforms have their own rules regarding word limits and the form of sharing. For example, Instagram always requires the user to share a picture and blogs allow parents for long narratives whereas Instagram and Facebook posts tend to be shorter. One of the rules that is of interest here has to do with the recontextualisation of knowledge. Recontextualising knowledge gained in other activities (for
example anatomical descriptions of a heart defect or facts about treatment) is common here and there is no predefined way of how recontextualisation should take place (for example if sources should be referenced). Acknowledging the boundary crossing and the recontextualisation of knowledge is not important for all writers; what is important is the knowledge itself and the way it is used for self-expression.

The division of labour in the activity allows the parents to have ultimate control of what they share and of how they do it. They can choose all from the social media platform to the language used and the content to be shared. The parents are the experts here and their expertise can be both of an experiential and of a medical nature. Some of the positive outcomes with the activity of sharing knowledge in terms of learning are the possibility to process facts and to gain better control of one's experiences and emotions, reaching a deeper level in the practices of doing health literacy. Recontextualising one's knowledge and experience and transferring it to others can also have an emancipatory function, as it potentially allows parents to feel useful by offering something back to the community of the activity. At the same time, the roles of novice and experienced are not only attributed to the community members in relation to their parenting experience, but also in relation to their participation in social media as a literacy practice. A by-product of co-constructing knowledge about children's heart defect is the acquired meta-knowledge about what one is expected to do and say when acting in this context (Säljö, 2012).

5. Discussion

In this article, we have concentrated on how parents of children with heart defect construct knowledge about their child's condition. Our aim has been to show that knowledge about health is not accessed by participation in isolated activity systems, but it is a cumulative process that takes place through boundary crossing and recontextualisation between networked activities. Engaging in health literacy practices means more than just learning facts about a medical condition. It often requires a combination of different kinds of learning that together lead to a broader picture about having and living with the condition. We see the learning that takes place as expansive (Engeström, 2001), because the path to knowledge is not designed in advance but it is built up in the process of taking decisions and actions about one's health.

The knowledge accessed in each one of the activities in which the parents participate depends on the mediated tools available in each activity. In the consultation session, the main mediating tools that enable parents to learn about the diagnosis are the medical experts and the oral interaction during which they explain the diagnosis and possibly the treatment. Additional mediating tools are the heart sketch and the parents' questions to the doctor, which bring them closer to the desired object of learning about heart defect. These tools are mediated by medical experts in a medical institutional context and thereby result in access to medical knowledge. In the online activities, learning is mediated mainly by the large community of parents with similar experiences and with digital tools such as social media. These tools can be used to construct knowledge with help from other people's lived experiences and lead to learning about concrete events, feelings and dilemmas about everyday life. When visiting websites run by medical experts the knowledge accessed is again more of a medical nature. In other words, we have shown here that the knowledge that can be accessed in each activity system is directly related to the mediating tools as well as the activity's community, rules and division of labour. When the desired object of learning expands then the subjects need to either extend the activity or move to a new one in case the right tools do not exist or in case the rules do not allow for new mediating means to be introduced in the activity.

The consultation activity takes place in an institutional setting run by long-established rules that cannot be easily bend or changed to fit the purposes of each individual subject. For example, the medical experts are not allowed to express an opinion in relation to late abortion and they are only expected to give facts and qualified advice in relation to the diagnosis. Additionally, the cardiologists' professional role does not extend to taking up questions of moral, religious or emotional dilemmas in relation to the heart defect. This is why the consultation activity does not provide the right mediating tools in case a parent wants to address such questions that lie outside the doctors' medical expertise. The activity is rigid to the extent that it cannot be easily expanded. The contradiction between the parents' new needs for learning and the rules as well as the tools available in the activity leads to a small expansion, the experts cross boundaries between activities by guiding the parents in their online searches. The new desired object needs to be addressed in a new activity where the parents will be given access to a new kind of knowledge.

Our study confirms earlier studies (see Section 2) that argue that doing health literacy in the information society is comprised by a set of complex practices that are enacted in diverse contexts. Studying such a polycontextual set of practices makes it a difficult analytical task to point to a concrete and stable object for the activities under study. This is especially true since the main object that we seem to be dealing with here is learning. Learning about a specific medical condition is not as a concrete object as the prototypical objects in activity theory that emerge first from the agricultural and then from the industrial world (Spinuzzi, 2011). In the information society, knowledge is the core value for participating in any human activity and functions often as a mediating tool but also as an object in human actions. In the consultation session we could have argued for the object of the activity to be the actual consultation. However, our aim with this study is to look beyond what happens in a medical consultation context. What we want to achieve is to show how parents learn about their children's condition and this is the reason why we see learning as the main object or sometimes the motive in all activities examined here. Learning, however, cannot be discussed as a tangible and stable object. When engaging in a situation where one wants to gain knowledge about a subject, it is not always possible to know in advance what one needs to learn. This means that the object of learning can take many different forms, it can be concretized, and it can be adjusted to fit the subjects' needs and the activity's mediating means. How can we study an activity when the object is diffuse and unstable? Spinuzzi (p. 464) argues that knowledge work objects are less material and more multiperspectival. Multivoicedness is a key term here in order to understand how the object keeps taking new forms. Engaging in health literacy means entering activity systems where both experts and non-experts are equally but differently qualified members of the communities. Our analysis has shown that learning about heart
defect takes place as much from medical experts as from other non-experts. In activities with high degrees of multivoicedness, the subjects often enter in dialogue about the nature of the object (Engeström, 1995). We have shown that the consultation session is often such a complex activity where medical experts and parents have different ideas about what constitutes learning about one's health. This seems to be the reason why new activities come in play, activities where the main object of learning remains the same but where the possibilities for learning are different due to new kinds of mediating tools and different structure when it comes to rules, community and division of labour.

Not being able to point stable and large activity systems is not seen as a problem here but rather as an interesting result. The blurry limits of the online activity systems and the continuous crossings and contextualisations between activity systems tell us something important about the stable and large activity systems. They urge us to see health literacy not as a practice enacted in well-formed, separate activity systems, but as a number of practices that take place in a network of activities and contexts. In fact, doing health literacy in the information society has taken such broad dimensions, in relation to the contexts in which such a practice can be enacted and in the activities that can be involved, that we could argue for health literacy to be seen as what Engeström (2006) calls a “runaway object”. Runaway objects are objects that occupy and concern a large number of activities, they are broad in scope and difficult to pin down in singular contexts. Instead, they are polycontextual and are characterised by a very large number of subjects and communities being engaged in achieving them. In Engeström's words “they are objects that are weakly under anybody's control and have far-reaching, unexpected side effects” (p. 1784). Doing health literacy in the information society can indeed be argued to be such a polycontextual object, an ideal that preoccupies researchers from all sorts of disciplines, medical experts, the institution of the health care sector and individuals. It is enacted in contexts such as hospitals, medical associations, homes and virtual environments. It is also enacted in a number of activities, such as medical examinations, consultation sessions, online searching and blogging. Engeström further argues that runaway objects can “generate opposition and controversy” but they can also be “powerfully emancipatory objects that open up radically new possibilities of development and well-being” (p. 1784). This is true for the object of health literacy, which can be both restricting when seen as a skill that is to be possessed in order to adequately take care of one's health, but also an affordance when seen as a set of practices that may gradually lead to development and learning.

Studying health literacy as a runaway object calls for a broader research focus that expands over the limit of single doctor-patient encounters and specialised written genres, such as medical documentation and health blogs and family forums. Instead, the study of health literacy requires rich and diverse data that will highlight the large number of activities where it is enacted as well as the networks formed between activities and the ways boundaries are crossed and tools are recontextualised. The data should also highlight the diversity of mediating tools in each activity, the different forms that the community can take and the ways that rules and division of labour shape people's actions. More importantly, the study of health literacy as a runaway object should point our attention to the way new smaller-scale objects are constantly developed in unpredictable ways. It is only by taking such a broad approach to data collection and analysis that we can argue to understand expansive learning, that is how people build up knowledge gradually, continuously and at various levels in the information and knowledge society.

Acknowledgement

The research project was funded by The Swedish Research Council (Vetenskapsrådet, VR) 2015–2017.

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