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Becoming the expert constructing health knowledge in epistemic communities online

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ABSTRACT

From a discourse analytic framework, the article analyses health blogs and patient's forum discussions in which parents to children with congenital heart defects recontextualize medical professional knowledge and share their own experiences. The study show how the two types of online media may serve as a means for parents to attain expert status in their own case by sharing lay knowledge expressed as an amalgamation of the two key perspectives – professional and experienced – as an indivisible unit. Monological discourses, such as narrating, in blogs and more direct and immediate responses in forum discussions are noted as examples of differences in how medical facts are explained and negotiated, how advice is provided and how patient expertise is created. The study also show how blogs and especially forum discussions are used to problematize the validity of actions and opinions of medical staff. The role of developing patient expertise in epistemic communities online may therefore come with a risk of spreading misrepresentation of medical cases.

Introduction

During the last decades a wide variety of online communities have connected people who are far from each other geographically but close in terms of experience (Nieuwboer, Fukkink, & Hermanns, 2013). As information and communication technologies has taken a greater role in people's management of everyday matters the notion of lay-expertise has grown in relevance, not the least in the field concerning health and illness (Hardey, 2001). Health issues are today often negotiated in parallel with professionals in institutional settings like hospitals and among peers in activities taking place online (Kimmerle, Gerbing, Thiel, & Cress, 2012; Rains & Keating, 2011; Stommel & Lamerichs, 2014; Sundar, Edwards, Hu, & Stavrositu, 2007). Patient societies and self-help groups are welcomed as they enact patient autonomy and alternatives to standard doctor-patient relationships (Sudau et al., 2014). At the same time, they are often met with a concern of misguiding patients as a consequence of their lacking expertise to value the knowledge being shared (Nettleton, Burrows, & O'Malley, 2005; Schmidt & Ernst, 2004).

Knowledge negotiated by patients online has most often been described as lay-knowledge grounded in people's experiences from challenging health related problems of everyday life (Prior, 2003). When compared to so called expert-knowledge consisting of scientific and clinical knowledge lay-knowledge has been equalized with experiential-knowledge and described as 'knowing otherwise' (Baillergeau & Duyvendak, 2016, p. 410). Pols (2014) articulate patient-knowledge, as a particular episteme and describes it as 'daily practices of knowing' and 'knowing in action' as opposed to 'a body of knowledge' (p. 75). 'Expert patient' policies aiming to improve patient's self-management has made the assumption that when patients are influenced and shaped by medical knowledge patient knowledge can be considered the same as medical knowledge (Edgar, 2005). Studies have shown that this is not how it works. Analyses of patient practices (Groth, Sarangi, & Isaksson, 2016; Thomassen, Sarangi, & Skolbekken, 2016) offer glimpses of the differences between patient knowledge and medical knowledge obtained from professionals and point to the tensions between professional expertise and patient expertise due to increased complexity as to what counts as pertinent knowledge, what channels are considered reliable and viable, and how knowledge is distributed among different actors.

In this paper we discuss what signifies patients', in our case parents', knowledge development towards patient expertise in two types of online media – blogs and forum discussions operated by parents of children with congenital heart defects.

Health blogs are well established platforms used in the production and negotiation of patient knowledge. They are often written in the style of long narratives and accounts of personal experience of living with a specific disease (Miller & Pole, 2010). Health blogging provides the writers with an opportunity to receive support and advice from readers but also to contribute by reaching out to others in need (Pettigrew, Archer, & Harrigan, 2016; Rains & Keating, 2011; Sundar et al., 2007). One motivation and goal mentioned by both writers and readers of health blogs is an interest in learning (Pettigrew et al., 2016). Although blog posts are single authored they feature a strong sense of collective voice, peer review and cross-referencing of other blogs and other online sources of information, including medical professional websites (Sundar et al., 2007).

Health forums are used for support, defined in terms of information, advice, confirmation and empathy (Carlsson, Landqvist, & Mattsson, 2016). Online health forums have been described as practice-oriented communities where processes of collaborative learning and knowledge construction take place (Stommel & Lamerichs, 2014). In their analysis of forums on sport-related complementary and alternative medicine Kimmerle et al. (2012) revealed that soliciting opinions and advice based on single experiences and anecdotal accounts was taken just as seriously as evidential medical knowledge. This may raise concerns about the status of layman expertise as it is constructed in forums. Kimmerle, Bientzle, and Cress (2014) reflect on how experience-based advice is responded to, and the more personal or private an account, the more emotional response, indicating a tone of layman expertise of informality and emotion more than is the case in professional expertise. On the other hand, in order to be validated as core members of the community participants are expected to communicate relevant insights and knowledge on a non-trivial level (Stommel & Lamerichs, 2014; Landqvist, 2016).

A great deal of re-contextualization and re-interpreting take place in health forums. From an outside position the knowledge exchange may seem 'pseudo-scientifically

based' and appear doubtful as knowledge construction is a prominent means of people sharing beliefs and opinions (Schmidt & Ernst, 2004). Although the bulk of content in health forums seems to contain personal experiences, reference to various sources are made. Quantitative research on a large corpus of health forum posts (Sudau et al., 2014) show that most links distributed leads to social media sources such as Facebook and YouTube. Thus medical expert knowledge is also referred to/voiced, asserted, integrated/taught, evaluated/questioned or processed and links to professional web pages distributed.

The parent blogs and forum discussions on children's heart defects examined in this paper are similar in that medical claims about diagnoses, prevalence and prognoses often are presented as central concerns, although knowledge from everyday life with the child is as much an issue (Bellander, Karlsson, & Nikolaidou, 2018; Landqvist, 2016). It is therefore possible to describe the development of patients' expertise through the study of them. In health blogs, expertise is often shown in narratives and reports from the blogger's daily life with a specific child. In health forums expert information is requested and negotiated in interaction among participants providing each other with knowledge (Kimmerle et al., 2012; Stommel & Lamerichs, 2014). As a guideline for the analysis of knowledge sharing and knowledge management we apply the concepts of *Community of Practice* (Wenger, 1998; Wenger, White & Smith, 2009) and *Intertextuality* (Fairclough, 1995).

Aims and questions

The aim of the study is to explore the prerequisites for knowledge building and the emergence of knowledge authorities in patient epistemic communication online. This is done by describing and comparing knowledge discourses in parent blogs and forum discussions on children's heart defect. We focus on sharing knowledge on health issues in processes of integrating medical knowledge into the lived experiences of expert patients, asking: 1) how medical and experiential knowledge is recontextualized, and 2) how sources of knowledge are compared, problematized and negotiated.

Key analytical concepts

In this section the overall concept of community, especially epistemic community, is defined. Here is also described how the notion of expertise, notably patient expertise, can be conceptualized and framed within an online community. Finally, intertextuality as a guiding analytical tool is presented and operationalized.

Epistemic communities online

Digital technology facilitates the construction of communities, where groups of people who share common interests gather to learn more about that interest and improve upon its practice (Wenger, White, & Smith, 2009). A Community of Practice, CoP, brings together people who are looking for learning companions, in our case people learning to be parents of a child with a heart defect. By 'hearing' each other's day-to-day stories and comparing them to their own experiences, they learn *from* each other; by helping each

other understand, they learn *with* each other. Socializing and learning are not distinct in a CoP, where the learning connection is as salient as the process of community building. Leadership and, arguably, expertise are essential ingredients in a CoP, which can be formal or informal, concentrated in a few people or broadly distributed. In blogs, one person is responsible for the sharing of medical information and personal experiences, while in a forum discussion, the core group of active members shares in caring for the community. The concept of CoP has proven to be especially suitable for investigating knowledge constructions in social media since it offers a notion of community that is not static, not defined in terms of its members or membership structures but as a product of participation (Sharratt & Usoro, 2003; Stommel & Koole, 2010). According to the CoP theory of learning (Lave & Wenger, 1991), community membership provides access to diverse thoughts and expertise. It also provides the opportunity to be an expert with knowledge that can be put into the practice.

Shared expertise

A community may be more or less knowledge intense. Of concern in this study is epistemic communities (Adler & Haas, 1992). This refers to networks of people with expertise and competence in a particular domain (usually professionals, e.g., physicians). In analogy, the expertise of patients, parents and other lay persons, we take an interest in communities that create a shared set of normative and principled beliefs providing a value-based rationale for social action; shared notions of validity; and a common policy enterprise, that is, a set of communal practices associated with a set of problems to which the member's professional competence is directed (Adler & Haas, 1992, p. 4). Such communal factors, enabling communication between people with similar experience, are the starting point for the exploration of how participants both share knowledge, and expand and elaborate on this knowledge, as well as create new beliefs together. What might be called knowledge can be regarded as relative to the perspectives of those making the claims of knowledge. Miller and Fox (2001) argue that whenever a person states or claims something, that person does so from a certain standpoint. The perspective's view of knowledge rejects knowledge as something cumulative and progressive. Instead it can be considered a matter of a 'knower' within a community of other knowers. Knowledge is considered an intrinsic part of a person's perspective and particular experience of individuals.

Networking in specialized online communities, such as blogs or forums, implies certain norms for participation. Legitimate posts are expected to communicate relevant insights, knowledge and even expert discourse on the issues under discussion (White & Dorman, 2001). Therefore, participants may be required, albeit implicitly, to possess more than general knowledge about the subject at hand – perhaps also unique experiences and the ability to communicate them, be it in insightful questions or supportive responses (Landqvist, 2016).

In our study, we use data from blogs and forums where the focus is on medical knowledge. Bloggers and forum participants share knowledge and perspectives from their positions as parents of children with heart defects. Intersubjective, internal criteria for evaluating knowledge and shared practices, patterns and readiness for action can be associated with problems and shared competences (Haas, 1992). In some cases, such shared, mutual competence in an online community has been found to bring about

joint action in political contexts (Akrich, 2010; Bennett & Segerberg, 2012; Vicari & Cappai, 2016), especially when patient groups and their medical and other social communities are involved.

The notion of sharing has been described as a key activity in online media. John (2013) uses two definitions of sharing whereas the first involves the distribution of links, photos and video clips and the second involves communicating feelings and opinions about current events. While the first definition entails 'letting someone else have something that you have' the second definition cary 'updating one's status', 'telling' and 'letting people know' (p. 170). In this study the notion of sharing is examined by focusing on what aspects – that is, what content – parents to children with heart defects choose to share.

Intertextuality

A point of departure for this analysis is intertextual links (Fairclough, 1995) made by writers in blogs and forums and the recontextualization of information and potential knowledge (Sarangi, 1998). In positioning oneself as an expert, and thereby contributing to a community of peers, the use of sources of knowledge is paramount. Sources can be experiences learned from one's own or others' specific cases, such as experiences from caring for a child, professional expert advisory texts, meetings and consultations with medical practitioners a.s.o. Links from those sources of knowledge are here paid special attention, along with how they are framed and presented in the data. Intertextual links and their recontextualization are viewed as a result of certain choices and foci made by the writer (Sarangi, 1998). In this way, links can play a specific communicative role in the text, such as grounding an argument or establishing information as fact or knowledge.

Since the aim of the study is to explore and compare how knowledge authorities are constructed in blogs and forum discussions on children's heart defect, prerequisites for knowledge building and the emergence of expertise in online communication will be in the core of the analysis. Linguistic criteria for identifying and coding *intertextual links* and the functions of *recontextualizing knowledge* are means for identifying how patient expert discourses concerned with issues involving children with heart defects are constructed. Linguistic markers support the analysis in indicating how information – both from medical professionals and from the participants' own experience – is constructed, evaluated, used and potentially transformed into knowledge considered of value to the community. Markers of direct reference, such as verbal processes like 'said', 'claimed' etc., have been acknowledged since they may indicate how information from e.g., medical professionals is perceived by the parents. Similarly, markers of perception, such as 'see', 'think', 'know' etc., may contribute to the image of how knowledge is conceived of by the sources referred to. Markers of evaluation in connection with the above mentioned may contribute to the analysis of how information is related and made coherent. Likewise, markers of emotion, affect and the like indicate attitudes, and the use of medical, technical terms might show the writer's' familiarity with medical discourses.

Data

The data was collected for the Swedish linguistic research project *Health literacy and Knowledge Formation in the Information Society* (funded by the Swedish Research Council

2015–2017). The project in large holds a variety of texts from webpages and social media and ethnographic data such as interviews and recorded medical consultations. For this study we use 13 Swedish 'heart child-blogs' and two discussion threads from a forum addressed to parents of children with heart defects. Both blogs and discussion threads were collected between February 2015 and March 2016 using a search engine and the keywords 'heart child' ('hjärtebarn') and 'child with heart defect' ('barn med hjärtfel'). All results in this study comes from this data, which to our knowledge is exhaustive regarding the keywords used.

The blogs were written by parents and they focus primarily on the child, not the life of the blogger in general. The children range in age from less than one year old to primary school age. Some writers started blogging during their pregnancy and some after birth. The children suffer from different kinds of heart defects and have gone through different stages of treatment.

The forum data is from the Swedish social network Familjeliv.se ('family life') that is open to anyone. Any kinds of issues related to parenthood, reproduction and childbirth can be raised in this forum, which is why the issues depend on what questions and replies are submitted to the forum and emerge from the interaction. The two relatively long discussion threads that we used for this study focus on life with a child with a heart anomaly, a condition that requires a high level of parental vigilance and constant care, since nutrition and blood values, for example, may be affected.

Analysis

In this section excerpts from blogs and forums are examined with the aim of describing how health knowledge is built and how patient expert discourses are constructed. Sharing and negotiating expert knowledge are main points of the analysis in two separate sections focusing on blogs and forum discussions respectively. We conclude the analysis with a comparison on how patient expertise is constructed and developed in the two media formats.

Knowledge building in blogs

The sharing of medical knowledge in health blogs is most often interwoven with personal experiences of some kind (Sundar et al., 2007). The practices of writing blogs are contingent on what medical expert knowledge the writer has absorbed, given his or her own case. In excerpt 1 a writer presents medical knowledge while telling about a visit to the clinic for an ultrasound:

(1)

Yesterday **we met the cardiologist** [**first and surname**] again. **He performed** another ultrasound on the heart [of the fetus]. **It's getting hard to see** now because his ribs create shadows in the image. **What we could see** though is that there is no leak between the right ventricle and the right atrium, which is positive, **they cannot see** a constriction in the atria and that is very important. If there had been [a constriction in the atria], the situation would have been different. Even the flow to and from the lungs seems fine, but **this was difficult to see**. We will go back for a final check-up in about a month.

Excerpt 1 shows how references to medical observations, marked in bold, are made in telling about the experiences from the examination. The writer demonstrates familiarity with medical discourse by using medical terms such as 'right ventricle' and 'right atrium' while presenting medical facts about the specific heart. The concrete perceptive act 'see' is used as the main intertextual link to professional knowledge: 'we could see', 'they could see' and 'this was difficult to see'. References are made to a specific cardiologist, and at one point the writer uses the pronoun 'we', indicating that not only the cardiologist but also the writer and his/her partner were able to interpret the ultrasound data. S/he relates what was seen in the examination to what was not seen – 'they cannot see a constriction in the atria' – and evaluates this finding as 'very important'. By using the logical conjunction 'if', s/he explains how the heart condition could have been different. By using medical terms in addition to the experience of having seen the fetus's heart with his/her own eyes, the writer makes the case relevant and makes her/himself trustworthy to other readers.

Excerpt 2 illustrates a blog writer's previous access to specialized knowledge, here recontextualized and integrated in the blogger's repertoire of content to share with others, and thus constructed as valid knowledge:

(2)

The tube that we feed him through is narrow and goes through one of his nostrils to his stomach. The picture shows the white tape that holds it in place, it is there to prevent him from pulling it out, which he tries to every so often. This particular tube is special since it also contains technology. **There are four thin electrodes that sense the signals in the stomach sent from the brain to the diaphragm to initiate a breath. They can be connected to the respirator so that the signals can be synced to puff oxygen when [name of baby's] brain tells his body to breathe in.** Clever as heck. At the moment it's not needed since he breathes on his own but, according to my information, this type of tube costs SEK 2,000 each so they will not throw it away yet, in case it might be needed later.

Excerpt 2 refers to a picture of the child connected to a respirator through a tube. The shared blog post is designed using specialized terms – such as 'thin electrodes' and 'diaphragm' – as well as an informal style – usage of the baby's name, and expressions like 'clever as heck'. No references are made to expert sources except quite indirect ones, 'according to my information'. The writer constructs information as valid knowledge at a non-trivial level which is integrated into her/his own repertoire.

Although most writers in the blogs examined express their satisfaction with medical professionals and recontextualize their information as valuable, there are cases of dissatisfaction in our data. These are of particular interest to our study since they form grounds for increased awareness. Perhaps thanks to the generous blog format issues are often problematized in a relatively detailed way. In excerpt 3 a writer reports on a meeting with a doctor who is referred to directly.

(3)

Oh the worries we had back then [last year]; we felt that things were not the way they were supposed to be and that something was very wrong […] we sought help and **according to the doctor there was nothing wrong with her**, a bad cold was the first diagnosis, then she was diagnosed with asthma and after that they suspected [a] gluten [allergy]. **It is frightening that a doctor can say such things to parents without even doing any proper examination**.

> […] but as a parent, worried, scared and dejected you rely on doctors, **they should know these things, right?** But unfortunately today, we have difficulties trusting doctors.

The doctor is referred to both verbally, 'according to', and mentally, 'they suspected'. The child's diagnosis seems to have changed during the visit, and this lack of precision is underscored by the choice of the word 'suspected'. The doctor's evaluation, 'a bad cold' and later 'asthma' and 'gluten' is commented on and found to be without grounds, 'without even doing any proper examination'. This in turn is viewed as a general problem, since 'trusting the doctors' is difficult. Obviously, the journal entry format of blog entries allows writers enough space to tell their whole story. Therefore, it may be easier to juxtapose information from professionals with the experiential knowledge the writer has gained on her/his own. This writer does not show any integration of knowledge, but rather a more personal stance as a worried parent.

In conclusion, recontextualization of professional expert discourse is framed as a valuable resource for one's learning and ability to contribute with pertinent pieces of knowledge to potential readers. The excerpts indicate that patient expert discourse emerge in the amalgamation of those two sources of knowledge. However, there is another function: taking doctors' advice as a ground for criticism. In this way professional knowledge can be regarded as a reference point to evaluating the parent's experiential knowledge. The blog can therefore be considered a format for using intertextual links to form an alternative to or justification of how existing expertise should be viewed.

Knowledge building in forums

As in the case of blogs, a frequent way of constructing and sharing medical knowledge in forum discussions is by referring to medical professionals in a more or less problematizing way. This is done by creating intertextual links and marking verbal acts of the professionals, as well as recontextualize information in a negotiating manner. This is illustrated in excerpt 4 in which past experiences and meetings with medical experts are reconstructed as key knowledge and now ready to be shared with others.

(4)

A: Since January we have done the dosing ourselves and the lowest value has then been 2.4 and highest 4.0 – **I consider** that totally OK and reasonable, since she has fluctuated within the middle range. We as parents see their general status and then, as [initial of previous writer] writes, one may be a little bit cool and view cause and effect in another way. **If the PK value is low today, it means that** something happened 3–4 days ago, right? Probably the child is already on the go again.

B: Exactly, we parents learn how our child's value is affected by this or that. **We give Fragmin at 1.8 and lower since he has a mechanical valve** and increase the dosage a bit, but **values up to 4 are not unusual** in some cases, right? However, he is often quite stable if we leave the dose unchanged for the smallest things. Mostly the body takes care of this on its own, after a couple of days. But **if one sees that the value is constantly high or low then** one will have to increase or decrease the dosage a bit.

In excerpt 4, medical experts are absent. Instead writers A and B present themselves and other parents of children with heart defects as people who know how to proceed when dosing with Fragmin – for instance, 'I consider that totally okay', 'we as parents see

their general status' and 'we parents learn how our child's value is affected', using intertextual links to this experience such as 'I consider', 'we as parents see' and 'we parents learn'. Both A and B acknowledge that they need to be vigilant about the child's condition, measure the PK values and be able to act on this. However, B's view is that it is wise to act in a cool way, since too many and too hasty readings might be counterproductive. This is indicated and marked by logical and epistemic markers i.e., conditional clauses and logical conjunctions such as 'if … it means', 'probably', 'since', 'if … then', appearing in claims of knowledge. The negotiated knowledge is a combination of professional empirical knowledge and personal experience. As a result, the interaction resembles the typical advice from an expert who deals with medical problems calmly. In addition, knowledge is projected as totally beneficial to the participants. It is shared with confidence and acknowledged as such by both writers.

Questionings and complains of doctors and medical advice in forum threads often concerns a lack of information. Although the posts seldom reject advice as such but rather show frustration with doctors not communicating enough this is an important step for the development of alternative knowledge and norms within the community. We consider this as a step in developing patient expertise. In excerpt 5, the forum writer expresses her/his discontent.

(5)

We seem to be unable to get **any clear information …** we have met with two cardiologists at [name of hospital] now and one of them says that our son very well may be a candidate for surgery before he is one year old, while the other one claims the opposite … **It is so frustrating** to get two different kinds of information :(Who should we trust? Is it the same for you guys who have children with "minor" heart defects?

The frustration expressed in excerpt 5 is not on perceptions or evaluations of professionals but on their actual reports which are viewed in rather critical light. However, the writer provides no information about what arguments the two doctors have presented. One possible reading is that it is up to other participants whether to advise or support the writer by sharing experience and other information. The position of this writer seems to be just that, one of reaching out for support from more experienced participants. The post may most likely simply serve to voice complaints about the generally awkward communication of doctors. This actualizes the discussion forum as a site for engaging in each other's cases, sharing experience and searching for and creating knowledge. Accomplishing mutuality in this respect seems to be conditional on the elaboration and presentation of information that others can recognize, identify with or respond to with their own experience from similar situations.

When the opinions and recommendations of medical staff become the object of a critical discussion in a more fundamental way, it tends to lead to new conclusions about how to be an adept parent of a child with a heart defect. In excerpt 6 the questioning of doctors increases as the interaction between two participants develops. It starts with someone noting that a mistake might have been made during another participant's visit to a specialist.

(6)

A: (…) but the PK level was almost 8, **why the h--l wasn't he given vitamin K** or something like that? Over 7 is really bad and then our daughter needs medical care and vitamin K. If she

bleeds easily from the bladder, nose etc. we are supposed to take her to the ER right away. It could be internal bleeding.

B: OMG now **it is really difficult. Fucking shit doctors!** The doctors in [name of city] know what they are doing, but the ones in [name of city], which is our local hospital, don't. They didn't do anything special, only just no Waran that day. They didn't even examine his stomach, well they squeezed a little, but nothing more. When the PK was down to 2.1 they talked about some shot, but never when it was this high!

The ruthless question from A, 'why the h–l wasn't he given vitamin K … ' seems to trigger the complaints that perhaps would have remained unexpressed otherwise. B's expression 'now it is really difficult' in referring to her/his state of mind indicates that s/he finds it okay to respond emotionally and critically about the local doctors, 'fucking shit doctors!'. Frustration about insufficient efforts from the medical staff – 'they didn't do anything special' – are mixed with a hunch that experiential knowledge from everyday life with a child with heart defect may be just as valid as professional claims. Doctors' knowledge and actions, combined with parental emotions, seem to be negotiated and create a potentially active stance in the forum, in which participants' experiential knowledge is upgraded as the most important one. In the continuation of this interaction in excerpt 7, this becomes even clearer. B continues to comment on and support the negative evaluation of the doctors:

(7)

B: When it is low below a certain level the children get fragmin shots so that the blood won't coagulate. This sounds **really frightening**, I think they are bad beyond bad here where we live, but it is all about them being so **overly cautious** that I get crazy about them. […]. The point is not that you should stop trusting them but as a parent **you must be seven times tougher, dare to stand up for yourself, question** [**things**] **if you don't feel alright.** Ask what is happening if the PK rises and what the risks are, too. They should have informed you about the status.

The criticism expressed in excerpt 7 is not just tough in its evaluation but is also explained by the attribution of unnecessary caution to doctors. The conclusion seems to be that, while doctors may still be trusted, it is important not to be too compliant with their recommendations; one should dare to question what is claimed in consultations. Questioning and a negotiating stance seems to be idealized, but who knows with what consequences? The knowledge constructed in excerpt 6 and 7 is that the experience of a parent is just as valid as the doctors' opinions. The result seems to be, no longer an amalgamation of information from different sources leading to useful and valuable knowledge, but rather a separation. One source is the professional caregiver, a source that is increasingly de-validated during the interaction; another is the experience not just of the one writer but of the many parents who deal with the daily reading of their child's PK levels. While this experience has proved to be useful and rewarding for some families, that position is not based on evidence from empirical research. This is a good example of the tension that may arise between different expert systems in online communities (Thomassen et al., 2016), in this case patient expertise and institutionally sanctioned expertise.

On the other hand, the two different sets of sources that are here contrasted, can also be assumed to be integrated parts of the parents' repertoire of knowledge. Otherwise it would be difficult to perceive and understand the potential consequences of the two stances.

Being able to define and compare different ways of taking care of the child presents a complex situation for parents in their daily care. However, this patient expertise is very close to action or, as in this excerpt, the instruction to behave critically and with toughness and to trust oneself more than the professional expert. This complexity may give rise to different views of how knowledge is constructed both generally in medical contexts and specifically when a sick child is involved. It is not difficult to see both risks and benefits with a relativization and questioning of professional expert knowledge.

The function of online communities based on excerpts like the ones in this article, seems to be a reinforcing one, as there seems to be a refinement of knowledge in the meeting between medical and patient expertise. New perspectives are encouraged and may create potential for action, be it civil or political (e.g., Akrich, 2010). Parents simply must play an active part in their child's treatment and not just accept what the professional caregiver finds necessary. The common stance is that medical advice must be received with a critical mind set. However, this can only be done when parents have gathered enough experience and knowledge of their own. If they have not, other participants may provide the forum with experience that others may share. The potentials for knowledge construction then seems to be a result of clinical activities, recommendations or information and people's reaction to treatment – all this in combination with conclusions drawn from the daily life with a sick child, shared for instance in a forum. Recontextualization thus seems to be a complex process, in which the relationship with medical institutions and online communities is renegotiated as long as knowledge is constructed and re-constructed (see Sarangi, 1998). What is evident in excerpt 7 is that one unsure, troubled parent finds a new way of looking at things thanks to the other parent, who assists in re-constructing it.

Concluding comparison of blogs and forums

When shared in blogs and forums, lay knowledge is expressed as an amalgamation of the two key perspectives – professional and experienced – as an indivisible unit offered to readers.

While bloggers often tell their stories in detail and with a focus on their own case, it is common that forum writers adopt a teaching role informing newcomers or discussing matters with participants who have the same level of experience. The blog posts does not approach a community of readers in the same instructive way as the forum discussions do. Instead they work as a means of conveying personal experience connected to a problematic situation. This may be because blogs have a different technical platform and different aims than discussion forums. Nevertheless, blog posts have the potential to create resistance to professional care. This is precisely the kind of comparison that contributes to the construction of epistemic communities, since it makes them unique – the entries consist not just of repetitions of expert opinions or claims about how these opinions or claims are understood, nore simply of an increase in the writer's medical knowledge, but are a reasonable way of evaluating experts, with experience used as the main measurement. Blogging has no obvious interactive function, still we suggest the reaching out to peers in integrating knowledge is a viable activity within an epistemic community of practice.

The forum threads seem however to have more potential to create a quite distinct patient expertise, in which a comparison between different sources of expertise are

made. The interaction format seems to encourage participants to follow each other's leads, to share similar experience and to develop joint stances to professional experts. In this process medical knowledge is much shared and integrated with experience, which seems to be a central factor in the development of patient expertise. Consequently, both blogs and forums integrate different sources of knowledge in patient expertise. However, in forum discussions the dialogue makes epistemic stance taking more relevant. There are no other clear differences in how this expertise is constructed in the two media.

Discussion

In this paper, we have explored the epistemics in online communities by examining how patient expert discourses on children's congenital heart defects are constructed in blogs and forum discussions. We have seen that online media may serve as a means for parents to these children to attain expert status in their own case. In order to do so, the parents need to validate information both from medical professional sources and from their peers. Kimmerle et al. (2012) found that advice that was claimed to be based both on knowledge from medical training and personal experience had an especially strong impact in the forum. This indicates that participants are in need of both professional advice and the experience of peers. Further, they may start to view their own experience as a valuable source of information in the process of knowledge construction, this is in line with the findings of Kimmerle et al., 2012, 2014. Online media does then not seem to be about creating a dichotomy of patient versus medical experts, although some of the excerpts analysed may seemingly point at this. Our conception of patient expertise may differ on some points to those of Baillergeau and Duyvendak (2016) and Pols (2014), as we have found that the integration, made by intertextual links to all available sources of knowledge and their recontextualization, is how such expertise is constructed. Along with the conclusion of Kimmerle et al. (2012) we however concur that the very incitement for writing a blog or engaging in forum discussions, is often to find alternatives to medical facts given by professional carers.

We have nevertheless found differences in how blogs and forum discussions may be helpful in creating expert patients. Both media seem to offer good opportunities for recontextualizing professional information on medical issues. In previous research, this has perhaps not been the primary focus of interest. Therefore, it might be useful to de-construct the dichotomy sometimes created between personal experience (so called invalidated knowledge) and more reason-based responses to medical facts (e.g., Kimmerle et al., 2014), since different aspects of knowledge are integrated in the social media studied here. Both blogs and forums provide concrete descriptions of life with a heart defect and knowledge is shared among equals (parents to children with a heart defects). Both blogs and forum discussions therefore conform to plausible standards from which participants could benefit in many ways in their path towards a patient expert identity. However, blogs seem to have a clear potential for integrating different sources of information and knowledge, and to present this amalgamation in coherent text. They seem though to have a more limited potential to create a community, given the mainly monological discourses, such as narrating, reporting and, sometimes, complaining. In forums, there seem to be opportunities for participants to get a more direct and immediate response to their thoughts and feelings, and reverse, to share experience, thoughts and opinions to others.

Forums are simply better formats for the comparison, negotiation and stance-taking to different sources of information.

We have observed that participants in both forums and blogs take responsibility for sharing information in a way that is framed as pertinent knowledge. This means that they have integrated medical knowledge into their lived experiences. A patient expert role can then be assumed in explaining medical facts, sometimes in detail, as well as providing advice to others. This kind of expertise seems to be contingent on access to medical expert sources combined with the specific experiences. However, there may be quite diverse consequences from different constructions of knowledge and the recontextualization of professional discourse in forums and blogs.

This may also be a good time to address some possible adversities of the view on experiential knowledge as central in medical decisions, some of which have been pointed out by Nettleton et al. (2005), and later e.g., by Kimmerle et al. (2012, 2013, 2014). Misunderstandings and incomplete pictures of the child's heart defect may be spread when participants claim specific knowledge, anatomical or otherwise, and share it with newcomers. If this goes too far, there is even a risk of direct incorrect information being shared among participants, particularly in forum threads, and false attribution of expertise to the source. To this might be added a risk of over-generalization, perhaps due to only a minority of voices being heard; that is, many parents with relevant experience may not engage in online media. In our final excerpt, example 7, there are indications of a degradation in the expert status of professionals, with participants claiming that they have a better understanding of the case than their doctors. This may be understood by other participants in the wrong way, i.e., a risk for misrepresentation of medical cases, the view that professional experts are superfluous and online communities becoming a base for growing dissatisfaction with medical care, and perhaps subsequently to open protests, involvement in public debate and more, whether this dissatisfaction is justified or not.

An advantage of the recontextualization of expert knowledge is a high level of concretion along with experience-anchored information, just as in any popular science discourse. However, there may be possible drawbacks. Medical care professionals argue that misunderstandings sometimes arise and that patients or their family do not have a complete picture of their individual case. This leads to our final point, that there are two contesting views of knowledge and validity. Viewed from the perspective of the professional practice, the validation of patient experts may be framed with a notable lack of scientific evidence, that is, positivistic evidence-based knowledge that can only be attained by medical professionals. On the other hand, knowledge arising from life experience may need only some of the medical data in a case; the rest is based on a patient's own experience and observations. Viewed in this way, patient expert knowledge is a useful, relevant and often a most welcome source of information for people facing a medical problem. It may be the very reason to engage in the epistemic communities provided by online media. The high level of integrated patient expertise among many of its participants is also a potential resource, not least for professional carers who could take benefit in numerous ways, e.g., as a complement to information practices.

Disclosure statement

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