

Blogging as a Health Literacy Practice

Identity construction and knowledge-building in the writing of parents of children with heart defect

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In our studies of health literacy practices among parents of children with heart defects, we noticed early that blogs were a recurring source for acquiring information (Bellander & Nikolaidou 2017). We also noticed that the parents in our study did not only *read* blogs, but some of them also *wrote* blogs. To regularly publish entries on a personal blog has been found to be a widespread activity within the area of health communication (cf. Miller & Pole 2010). We understand health blogging as a part of mass literacy in the knowledge economy (Brandt 2009) where building health knowledge is not only a matter of consuming information, that is by reading, but increasingly by producing knowledge, that is by writing. This is in line with what Brandt calls a significant shift in literacy activity where writing is ascending in importance, in relation to reading, and where the value of text activities lies in the doing of them rather than in the reading of them (Brandt 2009:157).

However, few studies have focused on the learning potentials in the act of health blogging. In this study, we aim to focus on how parents use blogs to produce and process knowledge by constructing identities. Receiving a heart defect diagnosis for one's child is a life changing experience and one that is bound to leave an imprint on a person's identity as a parent. Blogging is here understood as a means of expressing oneself and therefore as a means of processing change. We take a socio-constructivist view on identity formation and approach it as situated in the actors' socio-cultural context (Barton & Hamilton 1998). Identity is not understood as singular and stable but as plural and continuously changing and is therefore best studied in relation to the context in which it is being enacted. Writing is seen as a means of identity expression which is, to a varying degree, conscious and shaped by the writer's social context. There are many aspects that influence how people choose to portray themselves and thereby construct

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their identity in writing. In relation to health literacy, the construction of writer identities can tell us something about the different norms for knowledge mediation that co-exist in the modern information society. Identity construction in personal journal blogs has been studied mainly amongst young people and has focused on the way they express their adolescent, sexual and gender identity (e.g. Huffaker & Calvert, 2005, Chittenden, 2010). These studies show that personal blogs can be an important medium for learning – in the case of adolescents, for example, learning about themselves and about relationships to others.

In the present study, we investigate health blogging as a social practice, with a special focus on how identities are constructed, through sharing experiences and knowledge on the blogs. Our analysis of blogs and interviews, where the blogging parents reflect upon reasons for writing and ambitions with their blogs, seeks to answer the following questions:

- a) Which identities are constructed through blogging about children's heart defect?
- b) What kinds of discursive knowledge-building are enabled and made visible on the basis of these identities?

Previous research

Studies on health literacy that are anchored in a situated perspective show how engaging in health literacy practices involves complex cognitive, social, cultural and affective challenges for patients at multiple levels, including: disease domains, documentation, patient support, and the construction of patient identity (Papen 2009, Hunter & Franken 2012). Besides the ability to access, analyse and evaluate health information, health literacy also involves the ability to communicate messages in a variety of forms (Aufderheide 1993). The ability to transfer previous experience to written media in a specific context is fundamental to the act of writing a blog (Herring et al. 2004).

Health blogs have gained popularity by supporting long narratives and accounts of personal experiences along with information and commentary on health policy and health research (Stavrositu & Kim 2015). Blogs written from a patient perspective are rapidly increasing among various patient groups (Miller & Pole 2010). Motivations for writing health blogs that have received attention in previous research are for example *problem-solving*, *emotion management* (Kim & Chung 2007, Chung & Kim 2008), *community building* (Sundar et al. 2007), *information-sharing* (Chung & Kim

2008), *learning* (Pettigrew et al. 2016) and *campaigning* by disseminating information, collecting money and organizing events (McKenna & Pole 2008).

Health blogs written by patients or their family and friends are used for sharing both personal stories and medical information, although personal stories seem to occur more frequently (McKenna & Pole 2008). Blogging offers an opportunity to ‘write in depth’ and to sort and process health related problems. The act of writing a health blog has been compared to the established therapeutic method *the expressive writing paradigm* used in psychological treatment of people in crisis (Rains & Keating 2015). Psychologists (Nagel & Anthony 2009 and Tan 2008) argue that feelings of empowerment and relief by means of articulating one’s thoughts in a blog after experiencing a traumatic event are of therapeutic value. Blogging about cancer has been described as a way of creating networked narratives and engage in collective social action (Stage 2017).

Blogs are open to the public, which means that the writing can be followed by others. Writing a health blog means receiving support and advice from readers as well as reaching out to others in need (Sundar et al. 2007). Health blogging can also be viewed as being part of an epistemic community online where the writer’s medical professional knowledge is recontextualised and new knowledge based on one’s own experiences is created². Sources of medical information are often referred and linked to and sometimes also criticised. By sharing medical information and experiences bloggers perform an expert role. Besides disseminating information health bloggers act as campaign workers by using their blogs for activities such as mobilizing donations and organizing events (McKenna & Pole 2016).

The blogs on children’s heart defects examined in this article are written by parents and bear, in that sense, some similarities to the established blog category *Mommy blogs* (Friedman 2013, Lopez 2009). These are often described as informal, narrative and humorous. The fragmentary format of the blog and the daily repetition of the parental role emphasises an identity as a parent (Lopez 2009:744).

Blogging can be understood as a way of sharing parts of one’s life: events, views and thoughts. John (2013) refers to digital *sharing* mainly in relation to the technical sharing function in the modern web and points to the fact that it is fast and easy to share digital content that already exists online. The

² Discussed in detail in an article by Theres Bellander and Mats Landqvist, currently submitted for publication.

social practice of blogging means reaching out to other people, communicating with them, sharing one's opinions, feelings and current events. The difference between writing a personal journal and writing a personal journal type blog is that the latter includes the writer's intention to share the content with a wider public.

Theoretical framework and analytical tools

The present study adopts a social constructivist perspective of knowledge-building, and focuses on the construction of social positions in relation to producing and mediating knowledge (e.g. Berger & Luckmann 1967). As a general theoretical framework, we use the sociocultural paradigm of New Literacy Studies, which understands literacy as a social practice rather than an individual, cognitive skill. In this paradigm, identity is constructed in the linguistic aspects of discourse and multimodal semiotic resources, but also in other social practices in which writers engage in direct relation to writing a text, e.g. establishing contact with the reader, positioning oneself, expressing knowledge, emotions, etc. Using this principle as a starting point, we look for traces of identity construction both in the discourse in parents' blogs and in the way that the blogs and the practice of blogging are discussed in the study's interviews.

The social construction of identity as formed in writing and in other social practices has been extensively researched by the linguist Roz Ivanič. In her studies, Ivanič has shown that different forms of literacy foreground different aspects of identity and that these can be traced in specific discursive choices (1998:71). Identity is understood as a continuous process, shaped by events and moments in a person's life rather than as a quality. She uses the term *identification* in order to capture the transitions inherent in the process, turning identity from a noun to a verb (2006). We understand *constructions of identity* as temporary discursive positionings in this ongoing process, both in relation to what is said and in relation to the writer's self.

In her study of identity construction in academic writing (1998), Ivanič proposes four aspects of writer identity and argues that these aspects can also be tracked in other contexts of writing than academic. The first aspect is the writer's *autobiographical self*, that is the sense of who the writer is as a person, experiences of life, interests and practices, including literacy practices. The second, the *discursive self*, has to do with self-representation in the text, the impression we convey of ourselves when writing. Ivanič des-

cribes discursive identity as related to “values, beliefs and power relations in the social context in which they [the texts] were written” (p. 25). Elsewhere, Ivanič (2006) argues that the discursive construction of identity is achieved (amongst other strategies) by affiliation, that is the way we talk (or in this case write) like others who engage in the same practices. The third aspect is the *self as author*, which has to do with the degree of authoritativeness that writers put in their writing by establishing an authorial presence in their texts. Ivanič explains that the self as author is also part of the discursive self but she chooses to include it as a separate category as it is concerned with the interpersonal aspect of identity and can be implicated not only in discourses but also in social relationships of power (Ivanič 1998, Burgess & Ivanič 2010). The final aspect of a writer’s identity does not refer to individual writers but is located in social space. Ivanič calls it prototypical *possibilities for selfhood* and by this she refers to social positionings shaped by the writer’s socio-cultural context and which shape all three previously mentioned aspects of individual writers’ identities.

In our analysis of health blogs, we use these four processes of identification in the act of writing as a starting point in order to say something about the way parents shape identity when blogging about children’s health and thus when practicing health literacy. Due to the nature of our data, we mainly concentrate on the two aspects that are most directly traceable in the discourse of the blogs: *discursive identity* and *self as author*. We also reflect on *autobiographical self*, as far as our interview data allows. How these aspects are analysed is further described in the method section. The aspect of prototypical *possibilities for selfhood* is more briefly touched upon.

A discussion of identity construction in the process of blogging leads to a different discussion about the blogging parents’ learning practices. Identification with other people’s practices or with a community of practice implies participation in new discourses and participation, in its turn, leads to learning (Wenger 1998). In our study, we are interested in bloggers’ newly acquired knowledge in relation to heart defect, their role as parents to a child with a heart defect and the way they negotiate and give meaning to this role as part of their health literacy practices.

Data collection and methods for qualitative discourse analysis

The data consist of 13 Swedish blogs on children’s heart defects and interviews with six of the blogging parents. The blogs were all in active use and regularly updated at the time when they were collected: between February

2015 and March 2016. To find the most read blogs we used a standard search engine and the keywords *hjärtebarn* or *hjärtbarn* ('heart child') and *barn med hjärtfel* ('child with heart defect'). All the blogs collected were written by parents of a child with a heart defect and are focused primarily on the child and not on the life of the blogger in general. All bloggers regularly published blog posts at the time when the blogs were collected. Some writers started blogging during their pregnancy and some after their child's birth. The age of the children ranges from newborns to primary school age. The children suffer from different kinds of heart defects and have gone through different stages of treatment. The parents chosen for interviewing were the ones who were at a close reach to the researchers and who responded to our call for an interview.

Between May 2015 and March 2016, we conducted in-depth narrative interviews (Mishler 1984) with six of the blogging parents. We used open questions that enabled them to reflect on their blogging as a social practice, their identities as bloggers and their view of the functions of their blog. The questions aimed at promoting narratives, and were of the type "tell us about starting the blog, what was happening in your life?", "what were your intentions with the blog?", "what do you write about?" and "tell about the people reading your blog". The interviews were in average one hour long and they have all been transcribed. We will refer to the interviewed bloggers with the following names: Anna, Aydah, Chris, Elin, Sara and Vera. They are in ages between approximately 30 and 50 years old. Five are female and one is male. All six live together with the other parent. All six also have other children. Two of them, Anna and Aydah, have children that are younger than their "heart child". The interviewed bloggers live in different parts of Sweden and they have different economic, educational and sociocultural backgrounds. One of them, Aydah, is multilingual and uses both Swedish and Arabic in her family. Her blog, like all the blogs examined, is in Swedish. Two of the interviewed parents, Sara and Chris, have written blogs before. All parents are active in social media such as Facebook and Instagram. None of the interviewed parents say that they write other types of texts, besides their blogs and entries in social media, to any extent either for work or leisure.

Both interviews and blog texts are considered to be discursive accounts, produced in situated interaction. Reflective accounts on communicative norms, discursive roles and ideologies are made in both interviews and blogs. Thus, we do not understand the interviews simply as 'what the blogging parents say' about blogging and the blog posts as 'what they actually do' when they are writing. However, in the interviews, a more explicit meta-

discursive frame is often set due to the interviewer's explicit questions (cf. Hanell 2017:4–5).

The software ATLAS.ti was used for a thematic analysis of the interviews and all texts in the 13 blogs.³ The purpose of this initial analysis was to get an overall view of the content of the blogs, and a base for choosing text for further analysis. We identified four main types of content: texts about *the parents' everyday life with the child*, texts about *medical facts*, texts about *engagement* and texts about *feelings*. These main types are presented within an overall framing story where the “heart child” is the main protagonist (Bellander 2016). Other participants i.e. parents, siblings, doctors, nurses, preschool teachers etc. are assigned roles in relation to the child.

The four content types match the different functions of blogging, pointed out in previous research. *Information-sharing* (Chung & Kim 2008) can be seen in texts about medical facts, *problem-solving* (Kim & Chung 2007, Chung & Kim 2008) occurs in texts about the parents' everyday life with the child and *campaigning* (McKenna & Pole 2008) corresponds to texts about engagement. Texts about feelings can be interpreted as both information sharing and problem solving; by writing about feelings the blogger informs others on how it feels to be a parent of a child with a heart defect, as well as attempts to engage others in solving these problems. All bloggers write about their everyday experiences. Some are more inclined to write entries that contain medical descriptions, whereas others use their blogs mainly as a platform for emotional expression. A blog entry might start with a description of an everyday experience, which can be followed by a thorough medical description or by an outburst of feelings. Thus, the categories do not always match separate text units, but should be understood as abstract typifications. In the analysis that follows, we focus on blog extracts that represent all four content types discussed here.

In the analysis of *discoursal identities* constructed by the bloggers, these are understood as results both of how the writer depicts her- or himself as a character in the text, and of the social relations which are being enacted through discourse. More specifically, we are interested in the values, beliefs and power relations which are made relevant in relation to parenting, and how these influence blogging as a health literacy practice. The blogging parents' construction of discoursal identity is thus discussed not as a sum of original acts of writing, but as a means of affiliating oneself with other blog-

³ For a description of how ATLAS.ti can support discourse analysis see i.e. Paulus and Lester 2015

gers, parent bloggers and parents who do not blog. It is also important to note that our aim is not to arrive at typified categories of discursive identities in health blogs, as we, in accordance with Ivanič & Clark (1997), do not see self-representation as necessarily coherent. Instead, we argue that bloggers, similar to most kinds of writers, present changing and sometimes contradictory representations of themselves throughout the blogs. Neither do we view discursive choices in the blogs as indicators of health literacy skills, in the sense that certain discourses are linked to better health literacy. Instead, our aim is to show which discourses are in play when practicing health literacy and how they are used by the parents to enact identity in writing. In the blogs, we focus our analysis on discursive portrayals of social actors and social actions, whereas in the interviews we look for sequences where the blogging parents reflect upon their aims with blogging, give accounts of their writing processes and describe themselves as bloggers and as parents.

In the analysis of *self as author*, we look at whether bloggers put themselves in the centre of their writing and the degree to which they establish their presence in it, for example by attributing medical facts to other sources or by presenting them as acquired and therefore as owned knowledge. According to Ivanič, one way of understanding the difference between discursive and authorial self is to think about voice as a content in the first case and voice as form in the second (1998:331).

We also investigate the aspect *autobiographical self*, although it is made relevant to a lesser degree in our study, partly due to its design. The interviews with the blogging parents focus more on narratives around the diagnosis, the child's health condition and the blog, rather than on larger life narratives. We do, however, take account of who the parents are by making reference to their gender, ethnicity and earlier experiences on blogging when we present them as participants of the study. We also discuss autobiographical elements in the analysis, when the parents make it relevant for their blogging and when we can show how the autobiographical self plays a role in the discursive representation of self.

It is important to note here that the blogs were originally written in Swedish language and the extracts presented in this study are our translations. We believe that the questions we have asked and the discursive analytical methods that we have used, as described here, are not dependent on linguistic details on the level of the specific language. Therefore, translated extracts can in most cases be used without losing valuable meaning. In those cases where features of the original language are needed

for the analysis to be meaningful, we write the Swedish word in brackets (). All personal names and dates have been changed in the extracts. Names of places have been replaced with explanations in square brackets []. Square brackets are also used when parts of the interview sequence or blog extract is left out.

Identity and knowledge in parents' blogs

The starting point for this analysis is that the four content categories (texts about everyday life with the child, medical facts, engagement and feelings) differ to an extent that they constitute platforms for constructing different identities. Apart from focusing on the texts, we also search the interviews for extracts where the bloggers explain how they thought or what their aim was when blogging or when writing a particular entry in their blog. By doing this we aim to make a connection between identity construction and knowledge building when blogging about children's health defects. In the analysis that follows, we look separately at each one of the four content categories and discuss the different identities that bloggers can construct in relation to them.

Identity constructions while sharing everyday experiences. The most dominant type of blog content is parents' everyday life with the child. This includes recounts of visits to the hospital and accounts of everyday moments, thoughts and decisions. Entries about everyday experiences are typically narratives about events that have occurred in close time to the time of writing. In the interview extracts (1) and (2), the bloggers Anna and Vera say that they want to write their blogs from a parent perspective in contrast to a healthcare perspective.

(1)

Interv.: Um, okay, and how do you think that you want to contribute, I am thinking about your blog

Anna: I think I want to contribute with the parent perspective because all the other things I hope the health care can take care of, and I think that it is pretty important

Interv.: the everyday life with the child

Anna: yes and it is important to show that things can get out of hand but things can also turn out alright and it is worth taking the chance

(2)

Interv.: What did you search for on Google?

Vera: I googled the name of his heart defect Ebstien's Anomaly there was almost no information. Most of it was foreign information so, as for me, I almost got angry, everyone googles why isn't there something to find, someone has to write something but no [...] there will always be new people with heart defects and I know they will do exactly the same thing as we did and find nothing apart from the medical texts that you actually don't really understand and then I simply started a blog where I write how we experienced everything about everyday life and when we were there [at the hospital]

Anna points out her “parent perspective” as different from what “the health care can take care of” and she accepts the suggestion from the interviewer that her experiences from everyday life as a parent to a heart child can be of value to readers of her blog. Vera makes a comparison between information about everyday life with a heart child and information about medical facts. She places herself in a former position of having been someone in need of information on everyday life with a heart child and in a present position as someone providing this information to others. An aspect of Anna's and Vera's *autobiographical selves* can be seen to play an important role here. The experiences they have gained in their role as mothers lead them to juxtapose their knowledge with the institutional knowledge offered by the medical care. They orient therefore towards an identity as parents who know about everyday life with a “heart child” and who have the important task to show both positive and negative aspects of such a life.

Many blog entries represent everyday situations that are affected by the child's heart defect. In these blog entries, the parents perform *discoursal identities* of informed caregivers who adapt their way of acting in relation to different contexts. In example (3) from Lisa's blog, Lisa writes about her daughter's cold hands and feet as an implication of the heart defect:

(3)

Emma gets cold very easily. I know that all children get freezing cold hands and feet. Only few see that as a problem, it's worth getting to feel the ice, digging in the snow, splashing with water... of course Emma also wants to play without her gloves on. But because of the heart she has a bad blood circulation and she gets cold, so cold. Although she is wearing wool underwear, extra layers, fleece overalls, woollen socks and thick overalls she freezes sometimes so much that she cries. When we come indoors we need to flush hands and feet in hot water for a long time. Or give her a bath.

The child Emma is the protagonist in this narrative. The decreased blood circulation, an effect of the heart defect, makes Emma cold. This fact is embedded in a retelling of how Emma likes to play outdoors and how the parents have to flush Emma's hands and feet or give Emma a bath after coming inside. In the described situation, the blogging mother Lisa constructs a *discoursal identity* as an active caretaker; someone who knows that children with heart defects easily get cold when they play outside and therefore dresses her child in warm clothes. In the recount of the everyday experience she also gives herself the role of the one who solves the problem with the cold hands and feet. Lisa constructs a *discoursal identity* of someone who is aware, well prepared and in a position to intervene and act on her child's needs. In her blog entry, she shows that she possesses valuable knowledge that gives her tools to be in control over the everyday situation of playing outside with her child.

In a narrative recount of a medical examination at the local hospital (example 4), the blogger Ulrika writes about acting on a sudden medical decision made by a cardiologist.

(4)

Today we had a routine control with the cardiologist in [name of town]. It was rather quickly seen that there's too much liquid in the pericardium and that something needed to be done. A call was made in the [name of hospital] in order to find out what should be done. The decision to put Marcus in hospital ward 323 was taken, so it was fast home and pack, find a sitter for the dog and the cat and then drive at full throttle down to [name of town where the hospital is].

In this extract, as well as in example (3) above, the child with the heart defect is portrayed as the main character and as a child in need for help. However, in example (4) the one person in position to help is not the blogging parent but

“the cardiologist”. Unlike Lisa who can act on her child’s needs, Ulrika is not able to do anything about her son’s condition “too much liquid in the pericardium”. Instead “we” meet doctors, wait for and receive the doctors’ decisions and finally act on these decisions by engaging in practical matters, like “packing, finding a sitter for the dog and the cat and then drive at full throttle”. Similar to Lisa, Ulrika constructs a *discoursal identity* as an active caretaker. But unlike Lisa, Ulrika’s acting is not built on her knowledge of heart children’s special needs. A comparison of examples (3) and (4) shows an adaptation of acting to different contexts that is characteristic for the parents in the study. In situations like the one with the frozen hands and feet, the parents seem to be fully competent to care for their children’s needs, while at the hospital they leave the power to make decisions in the hands of the medical staff and they act upon the doctor’s instructions. They build identities in relation to the context and their capacity to act on their children’s needs. In some situations, these are *discoursally constructed identities* as caring parents who are aware, well prepared and in a position to intervene. In other situations, these are *discoursal identities* as caring but unprepared parents who are dependent on medical staff.

Identity constructions while sharing medical facts. Entries where the bloggers give medical descriptions of the heart defect, symptoms or treatment, i.e. medical facts, are shared to a fairly large extent on the blogs, although they are usually embedded in narrative accounts of experiences. The parents often include visual aids in the form of drawings of the heart and pictures of their child, in order to explain medical conditions. In the interviews, some of the bloggers categorise the sharing of medical facts as an act different from that of sharing moments from everyday experiences. Chris in example (5), talks about how he prepares the writing of blog entries that involves medical facts:

(5)

Chris: writing is also a way of collecting one’s thoughts and make it into a form that is understandable, so I guess, I sit down and I think through what has happened and what that means and then I’m like: “well this happened”, and then I might have to find out facts about that, so I do that and I put it in [in the blog]. I read the facts and then I reformulate it into my own words.

In this extract, Chris reflects upon his writing and describes it as a process consisting of several steps. It starts with Chris sitting down and thinking through “what has happened and what that means” where after he “might have to find out facts”. He does not say how he finds the facts, e.g. by searching the Internet or checking a book, but he describes how he reads and then “reformulates” the facts into his “own words”. In this extract, Chris specifically reflects on his writing process and he discursively constructs an *author identity* of someone who writes in order to find knowledge and make it “understandable”. He portrays himself as someone who takes responsibility for his own learning and achieves this by means of writing. His blog is open for anyone to read and later in the interview he shows that he is aware of his readers as when he, in example (6), reflects on different levels of background knowledge.

(6)

Chris: I sought information from many different sources and finally I had an overall picture. I am quite used [to searching for facts] and I’m pretty critical when I gather the facts. I have an academic education and I use critical thinking but when you think about it not everyone has that.

By talking about gathering information “from many different sources” and by being “critical” while gathering, Chris describes himself as an author who takes responsibility for what he writes on his blog. He explains this side of his blogging by bringing into play an aspect of his *autobiographical identity*, namely his academic background and his ability for critical thinking.

Constructing a strong and conscious author identity contributes to the discursive representation of someone who is informed and knowledgeable. In addition, Chris takes responsibility not only for his own learning, but also for the knowledge-building of others. In the blog extract in example (7), he explains the medical terms VSD and ASD:

(7)

VSD/ASD

VSD and ASD is usually called “a hole in the heart”. It is the most common congenital heart defect and can be found in 25% of all heart children. V stands for Ventricular and it means that the hole is in the wall between the heart’s chambers. There is another type of septum

defect where the whole is between the atriums and then it's called ASD, Atrial Septum Defect.

Chris' child is not present in the text. Instead, the main character is the child's heart along with different specific parts of the heart. In his explanation, Chris provides the exact medical terms: "ventricular" and "Atrial Septum Defect", by defining and explaining: "V stands for...", "...it means that...", "it's called", and by using everyday terms, like "a hole in the heart". He makes no reference to the source of the information. Instead he presents the facts as acquired, processed and integrated knowledge. In his writing, he constructs a *discoursal identity* as a layman expert, a knowledgeable person who can provide understandable information about heart defects. By writing the facts without directly connecting them to his own child and by using statistics to show prevalence, "25% of all heart children", Chris places his son's heart defect in a general context and makes the information applicable to unknown potential readers.

Like Chris, the blogger Elin seems to use her blogging as a way of making medical facts understandable. On her blog, as shown in example (8), she shares her own self-made picture of her child's unique heart. While introducing and explaining the picture by comparing it to a picture of a normal heart, Elin also gives an account of the process she went through in order to understand her daughter's heart defect:

(8)

It has taken us a long time to put together how the Princess's heart actually looks like and it became more difficult since there was no drawn picture with all the problems together and instead we got different sketches depending on which heart defect we were talking about. In the Princess medical journal from 15-02-17 you can read the following: "Truncus arteriosus type1 with rupture in the aortic arch. Open ductus. Complicated situation with a very dysplastic truncus arteriosus with a minor leakage and minor obstruction." In order to show what this means in practice I have put myself into doing a little sketch, I borrowed Growingpeople's picture of a heart with truncus arteriosus and then I drew the other defects. You can find more information on Growingpeople's heart page, all I give here is a short summary.

Elin describes her understanding of the heart defect as a process involving having to "put together" pieces of information during a long period of time. In consultations with cardiologists, the parents are often shown sketches

(Karlsson, Melander Marttala & Mattsson 2014). Elin writes that these sketches have been different, depending on which of her daughter's two heart defects the doctors have talked about. In order to fully understand the combination of the two defects, Elin writes that she used information from her daughter's medical diary. She also writes that she found a sketch of one of the defects online and that she drew "the other defects" on this sketch. Elin's *self as author* becomes visible here, as she adopts an academic discourse by providing sources to the information she cites. At the same time, she is not only copying facts, she is also creating her own knowledge by making the new sketch and claims therefore authority for her blog entry. In this way, Elin *discoursally* constructs herself as someone who is knowledgeable and takes responsibility for her own understanding to such an extent that she provides support for her own learning process. In her blog post, she does not only pass the information about the defect on to others – she also passes on a model for how to gather and synthesise information. Her *autobiographical identity* is also relevant here. Besides writing the "heart child blog" about her daughter, Elin is also the moderator of another blog where parents of children with heart defects are invited to write short narratives of their child's health adventure. Her experience as this blog's moderator and her contact with many parents to heart children appears to allow Elin to access, discuss and process medical knowledge possibly in an easier manner than other parents would do.

Identity constructions while sharing engagement. Some blog entries are written with a focus on engagement, where the blogger engages in a larger cause related to the child's condition. This can, for example, include requests for money or organ donations. Some of the interviewed bloggers seem concerned that few people have heard about child heart defect, as it is a fairly common but hidden disability, and argue that they want to make it widely known. This engagement does not originate in the bloggers' personal needs or wishes for their specific child. Instead their engagement can be seen as a collective action, a way of standing up for heart children in general. When reflecting on her blog writing in the interview, in example (9), Elin expresses feelings of unfairness when it comes to which children gain more attention.

(9)

Elin: but it is just that these statistics are not talked about, because only children with cancer count, really, of course that is horrible too but they are not as many if you compare and heart children are not talked about, really

Elin discursively portrays herself as a person with a mission. By mentioning “these statistics”, and by talking about “heart children” in general – not only her own child – she shows that being a parent to a child with a heart defect means, for her, being part of a community of people who are engaged in a larger cause. Thus, when the parents write about engagement in their blogs they construct a *discursial identity* of a person with a mission that goes beyond their own parenting. Parents of children with heart defects are dependent on help from medical professionals. At times when their children are hospitalised they are placed in the position of bystanders. When engaging in donation activities, the bloggers take an active position as someone who is able to do something for all heart children. This might be a way for them to compensate for the forced helplessness in relation to their own child. Example (10) shows how Gunilla, on her blog, writes about making stuffed animal cats for hospitalised children.

(10)

Now I am finally done making the Heart cats. My goal was to make five of them. The fifth one is almost ready too but I really don't think it turned out good. I used another type of yarn and it didn't turn out as good, so I don't want to send it. I might change my mind later but I am going to send these four cats first. But here we have Vida, Liv, Lycke and Gert. They are four small, cute cuddly cats that I hope will come to the delight of their future owners.

Gunilla uses a narrative to tell about the handcrafted cats she has made and donated. Along with a picture of the cats, she writes about the goal she had “to make five of them” and a yarn problem that occurred in her making process. In the two last sentences in example (10), Gunilla orients towards a marketing discourse that seems to be nowadays used even in charity activities. By shifting to an almost professional role in relation to making and donating the cats, she constructs herself as a person engaged in a cause larger than her own parenting.

Identity constructions while sharing feelings. In the blog types where the main topic is feelings and thoughts, the main character is not the child but the blog writer, and the focus lies on the blog writer's feelings. At the same time as the parents in our data often construct *discoursal identities* as strong and active, many extracts from both interviews and blog entries show positionings towards identities as emotionally fragile. Reflecting on their reasons for blogging in the interviews, five of the six parents express a "need" to write, more precisely expressed as a "need to get things out of their system". Some of them used the word "therapy" when talking about writing. In example (11), Ayda says that she often wrote in her blog as an alternative to calling a friend.

(11)

Ayda: I definitely get therapy from writing. I mean I felt relieved ('lättad') when I had written a blog post. I felt it was, maybe it has to do with my personality that I like writing so much, other people might call a friend instead but I didn't do that because I didn't feel like talking to anyone.

While Ayda uses the word "relieved" ('lättad'), Chris who also describes his writing as therapy, talks about "breathing space" ('andningshål') in example (12).

(12)

Chris: in my case it was pure therapy in a way [...] You get your thoughts on something else, or not on something else, but when you are in this situation you are so tense all the time you have to find some kind of breathing space ('andningshål').

The use of writing to be relieved or to find "breathing space" seems to be directly relevant to the bloggers' *autobiographical self* and is put into practice when they are in a sad, frustrated or angry mood. These feelings result in constructing a discoursal self of an emotionally loaded parent. Ayda says that she needed to write because she felt depressed. Christer talks about "feeling tense". The blogger Vera says that she writes when she is feeling bitter and angry and that she uses her blog in order to "ventilate" or to "get all the feelings out". Even if this would imply that writing is primarily for the parent's own sake, one of our earlier studies on parents' information seeking practices (Bellander & Nikolaidou, forthcoming) reveals that

parents want to read about other parents' emotional experiences, in order to prepare themselves for what might come in the future. Thus, there is no sharp border between self-therapeutic and communicative functions in the parents' blog writing.

In some of the blog entries, the blogging parents seem to be governed by their emotions and reactions. Feelings usually appear in narrative sequences, where they write about stressful or negative experiences or situations where they have felt strong emotions. In example (13), Sara writes about how she felt when her youngest daughter had to spend nights at the hospital, without her.

(13)

Now I am at home, in bed. Thea is sleeping between me and Marc ♥ wonderful! But every night I feel that a piece is missing. My other child is not sleeping with us. She is a long way from us in a hospital room together with a person she doesn't know. She is sleeping with a respirator and she needs constant attendance! I just want to go there and be with her! It is tremendously hard, tough, strenuous, pure hell downright! I want my beloved children with me twenty-four hours a day! We have come this far on this nightmare trip and we'll keep on fighting! I'll try to sleep a bit so that I soon can go to her, I miss her enormously!

I love my children above everything, they mean all to me! ♥♥♥♥♥

Sara places herself and her feelings in the centre of the text. Thea, Marc and the daughter with the heart defect, "my other child", are described in relation to Sara's physical position. Thea and Marc are close to Sara, in her bed, and "my other child" is far away in a hospital room. Together with "my other child" is "a person she doesn't know". This person probably belongs to the hospital staff but is not described from her/his professional position but from her/his relation to the child. Sara *discoursally* constructs herself as sad and vulnerable. She uses adjectives to describe the missing piece as "enormous" and the situation: "tremendously hard, tough, strenuous, pure hell downright". At the same time, she uses a collective "we" in the sentences "we have come this far...we'll keep on fighting". Sara seems to construct herself as vulnerable when being alone, but as a strong fighter when she is together with her family. Her *discoursal identity* as a mother with strong feelings is accentuated by the use of emoticons of small hearts and exclamation marks.

In some of the blogs, descriptions of emotional states and expressions for feelings occur outside of a narrative context. In example (14), Vera writes about her feelings, without connecting them to any specific event. Her text has a structure that evokes associations to a poem:

(14)

In the evening

That's when they come, the feelings!! Today it got worse than in a long time. It starts with a small thing that feels tough and ends with all the feelings bubbling up. Shit!



In the blog entry, Vera does not portray herself in relation to her child, who is in fact not present at all in her text. As opposed to writing about the specific emotional struggle of being a heart child parent (compared to Sara in example 13), Vera aligns with general discourses about the tiresome demands of always being strong. Vera places her feelings in a general and recurrent time context: “in the evening That’s when they come, the feelings” and “today it got worse”. However, exactly what Vera is feeling, and why, remains untold. Attached to the short text is a picture of a sad person sitting down with her/his knees up. The person is saying (or thinking) “And what the hell should one do when one isn’t capable of being so bloody strong all the time”. Vera’s choice of circulating a prefabricated picture, probably found online, makes it possible to interpret her expression of feelings as less individual, which opens for identification. In this extract, Vera constructs a *discourse identity* of a fragile and thereby a loving mother. The extract can be seen as a summary or as a culmination of feelings and events described in earlier blog posts.

Discussion

The aim of the study has been to explore how parents construct identities when blogging about their child's heart defect, and to examine what these identities tell us about the knowledge they build up. Like health blogs in general the heart child blogs support long narratives and accounts for personal experiences along with factual style information (Stavrositu & Kim 2015). They are written in a personal journal type style (Herring et al. 2004). Because of the strong focus of the children, the writer's identities as parents are emphasised. In this way, the blogs bear comparison to so called mommy blogs (Friedman 2013, Lopez 2009). In our analysis, it has been confirmed that different content becomes platforms for constructing different identities and thus portraying different knowledge. Before discussing this further, the results of the identity analysis will be briefly summarised.

The identity of an informed caregiver who can adapt the way of acting in relation to different contexts is best expressed in blog posts where the focus lies on moments from everyday experiences. When describing events that take place at home, the bloggers construct themselves discursively as fully competent to care for the child's needs. On the contrary, during events that take place at the hospital, they discursively construct themselves as subjected to the doctors' expertise and as parents who do not have enough knowledge to take own initiatives but act upon doctors' instructions. Often, this is accompanied by narratives of feeling helpless, probably since handing over control over one's child is not in line with the general norm of competent parenthood.

Writing about medical facts seems to involve conscious learning, where the blogging parents process medical knowledge to make it relevant to them as parents of children with a heart defect. The analyses of both interviews and blogs show that in these blog entries, the parents have the opportunity to construct *discursive identities* of well informed, knowledgeable parents who are responsible for their own learning. They possess the ability to gather information from different sources, critically value the facts they find and explain it in a way that makes the facts understandable to themselves and their potential readers. The identity aspect of *self as an author* is made relevant here, as the blogging parents often cite information that they have been given by medical staff or that they have found in other sources, such as the Internet. Here we find blog posts with a high degree of authoritative-ness, where the blogger presents knowledge as internalised and obvious and does not therefore make reference to the sources. On the other hand, we

also find blog posts where the bloggers adopt a more academic discourse and acknowledge their sources. When understood within the frame of helping others to learn more, making references to sources should not be seen as an indication of uncertainty or incompetence, but as a way of making their descriptions more credible and as a way of facilitating for other parents to orientate themselves in their search for information and knowledge.

When the blogging parents write about engagement in their blogs they construct the *discoursal identity* of a person with a mission that goes beyond their own parenting, and places them in a larger community. Their engagement can be seen as a collective action, a way of standing up for heart children in general. Parents of children with heart defects are dependent on help from medical professionals. At times when their children are hospitalised they are placed in passive positions as bystanders. As a contrast, some of them take active positions when engaging in donation activities. In these blog posts, parents also construct themselves as knowledgeable in terms of what kind of help is needed in this context and of how this can be achieved.

When writing about inner thoughts and feelings, the parents have the opportunity to *discoursally* construct themselves as fragile and weak or as strong fighters. The same blogger can alternate between both conflicting identities in different or even in the same blog posts. The knowledge that becomes relevant here is that of a parent that knows not only what to do in order to take care of a heart child, but most importantly how it feels to be this kind of parent. This is a knowledge that is unique to each parent but that seems at the same time to be useful to other parents who read these posts.

The new identities that parents construct by means of blogging tell us a lot about the new knowledge they have acquired and which they consider important to share with their readers, including other parents. On the basis of daily events and the identity as a competent parent who knows their child's best, the bloggers can process general knowledge and adapt it to their own, specific situation. When medical procedures are represented as part of feeding or clothing routines, they are placed within a real-life context, and also tested and found relevant. While health care providers can give information about what is common and what *might* occur, the blogger can tell about a real case, with a thick context and with events in temporal sequence. However, the lived experience provides little knowledge about the future. Thus, the *discoursal identity* as a critical gatherer of information and 'layman analyst', comparing facts and sketches, enables knowledge-building beyond the personal experience. In order to take on an *author identity* as

someone who provides broad and trustworthy information, the blogger needs to look beyond their personal situation. Interestingly, this widened scope makes them more prepared for processing new and unknown knowledge about their own child. The *discoursal identity* as a strong and executive activist, working for the best of all heart children, enables knowledge-building about the social and financial context of specialised health care and research. Finally, while reflecting on and analyzing their own feelings and reactions, and thus constructing a *discoursal identity* as vulnerable and yet struggling human beings, the bloggers can shift focus away from the medical context and, to some extent, away from their roles as parents, and focus on their own well-being and on the general challenges of coping as a person in a difficult situation. At the same time as being the most personal identity position, it is the one pointing to the widest interpretational context. This is underlined by the recycling of memes and quotes, not referring to heart child parenting at all.

The common theme in all four types of blog posts is that parents construct themselves as knowledgeable. Their child's health adventure has put them in a position to acquire knowledge that parents to healthy children do not normally have. In addition to presenting knowledge about heart defects, and different aspects of living with this condition, parents project in their writing new knowledge about who they are as parents as well as persons. For Ivanič, participating means reconfiguration of subjectivity and she argues that "learning to feel different about yourself, even to have a different sense of who you are is in itself a type of learning" (2006:26). In the case of the blogging parents, participation is achieved by means of blogging. Writing seems to be for them a means of processing events and information, but also a means of entering a community and both these activities lead to new knowledge, or else to learning.

The results of this study also tell us something about the conditions for being a knowledgeable parent to a child with a chronic disease in the contemporary society, since its case is placed in the intersection of family norms and communication ideologies. According to Westberg (2016), who has investigated the discourses of parenting in a Swedish context from an historical perspective, the 2010's Swedish public discourse about parenting is heavily influenced by a child-regulated parent position. This means that the child's need is put first, and that a good parent knows (or feels) what their child needs. This position is also commonly supported by experts and authorities, which means that there is no necessary conflict between following expert advice and listening to one's child. Both point to an indi-

vidually oriented way of being a parent, based on relevant knowledge and personal confidence. However, parents of children with chronic illnesses, such as a heart defect, develop different, more specialised, and more complicated relations to experts' medical knowledge. They need to relate to general knowledge, which is not based in their own experiences and individual preferences, and still they need to learn how the heart defect affects their particular child. In this way, parents of children with severe illnesses often find themselves in a position in relation to authorities that resembles the "normal" parent position of the 1940's in Sweden, when new scientific knowledge on parenting was produced, urging parents to break with old traditions and become modern, informed and educated parents (Westberg 2016:109 ff). This is not only a conflict between personal identities, but also a conflict between dominant co-existing ideologies in today's society: that of being a self-confident and child-regulated parent and that of being an informed and responsible patient.

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