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Parents' narrative about congenital heart diseases: Acquiring knowledge and sharing empathy[1]

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ABSTRACT

This paper tries to describe the narratives of parents with children who have a heart condition and who want to share their experience, as found at healthtalk.org, in order to detect how information, knowledge (and empathy) are deployed with the aim of helping other people in a similar situation to fill a cognitive and emotional gap. The investigation was carried out by detecting the most recurrent discursive patterns in the narratives, followed by an analysis of the most frequently used verb that best expresses parents' cognitive awareness (or lack of it) in their experience with their children with congenital heart disease: *know*. The discourses in these self-narratives follow an emotional flow which varies from story to story but presents a recurrent thread. This does not follow a precise chronological order, as flash-backs and emotions prevail in all the stories, but the main points are found in them all. The analysis of the most frequently used verb, *know*, carried out with Voyant, reflects the described narratives. The leitmotif underpinning all these points is the question of good parenthood: good parents are those who protect their children.

Keywords: discourse analysis, medical popularized discourse, corpus linguistics, empathy, online health communication.

1. Background and aims

I was born with a congenital heart disease which was diagnosed when I was just 6 months old. My parents had no idea why I had it and the only information they had was from the paediatrician who had diagnosed the

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disease. They just knew that my only hope of survival was a surgery to be performed in Houston, Texas, USA. When, in 1967, Christopher Barnard carried out the first heart transplant in the world, RAI, the Italian public service broadcaster, aired a late program on TV about that event with a commentary by, at the time, one of the most famous Italian cardiologists, Prof. Renato Donatelli. My father noted down the cardiologist's hospital address and wrote to him. The following month, the cardiologist visited me at Niguarda Hospital, Milan, where it was decided that a surgery could be performed: the following year, when I was 4 years old, I had open-heart surgery. Until the Milan visit, my parents had had very little support, nobody with whom to talk, or people who could give them either medical or psychological support. They were young and desperate; they got relevant information by chance from a TV program and took any decisions they thought were vital by themselves, and on the basis of what they knew. The choice to go to Milan was an odd one and the decision to have me operated on in Italy was taken because they trusted the cardiologist from Milan, who was characterized by an uncommon empathy, as they have always said.

Should this have happened nowadays, things would probably have been completely different. Support groups exist for any health condition and, in this globalized society, getting information is much easier than it was 50 years ago. Web 2.0 has become one of the most powerful resources when it comes to making sense of illnesses and has reduced patients' sense of isolation and their desire to find support (Jaworska 2018). As a matter of fact, if professionals use the Web to deliver information and awareness, laymen use it primarily for peer-to-peer support – which has demonstrated the presence of a disconnect in the use of the Web for medical issues (Robinson et al. 2016). Therefore, carrying out an investigation on the discursive strategies employed by the people who narrate their illness experiences online can be useful, as it may "shed light on what people do when they talk about illness online and how they do it" (Jaworska 2018: 25). The issue, however, is not so much or only to get reliable information, but also to seek and share empathy.

There is a growing body of literature on the dissemination of medical knowledge with the purpose of targeting general and specific groups with health messages (see, for instance, Thurnherr et al. 2016; Turnbull 2015; Daniele – Garzone 2016; Gotti et al. 2015), which is facilitated by online

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and change in discourse strategies, ideologies, and epistemology (COFIN grant no. Prot. 2015TJ8ZAS_002), directed by prof. Marina Bondi of the University of Modena and Reggio Emilia – local coordinator, prof. Maurizio Gotti.

communication, where the distinction between authors and audiences is less clear-cut. In this sense, health professionals are no longer seen as the only providers of healthcare (Harvey – Koteyko 2013). Indeed, in this context, knowledge dissemination is becoming a bottom-up process where laymen reinterpret and re-package medical information (Jones 2013; cf. also Turnbull 2015). While professionals are required to provide reliability and objectivity in health information, (potential) patients "are empowered not only to take more informed and responsible decisions about their health, but to actively contribute to knowledge construction and sharing" (Sokół 2018: 14).

The ways in which illnesses and healthcare are communicated outside doctor-patient interactions have started to be analysed in the literature with increasing interest, particularly in the cases of patients' first-person accounts of serious illnesses, which have revealed a better understanding of the subjective experience of illness (Appleton – Flynn 2014), cancer included, and of the sociocultural aspects of illness that may influence patients' self-perception and social relations (Hanne – Hawken 2007). Indeed, what is important, as also revealed in the corpus I have constructed, is not so much what people say, but rather *how* people – professionals or patients – say what they want to say (Sarangi 2004; Hunt – Carter 2012), which should also include the ways in which people report their illnesses (cf. Demjén – Semino 2017).

One reason why people turn to online health communities for support has been shown to be their desire to share and check relevant factual information (Lamberg 2003), but also to receive and express empathy (Rheingold 1993). As defined by Hojat (2007: 15, quoted in Pounds et al. 2018: 34), "empathy is a vague concept that has been described sometimes as a cognitive attribute, sometimes as an emotional state of mind and sometimes as a combination of both". As a cognitive or emotional phenomenon, empathy is the ability to understand someone's condition or emotional state without making it one's own (Hoffman 1981; MacKay et al. 1990). When empathy is explored from a communicative perspective, the focus is on how this understanding is communicated and how it shapes interactions. The core dimensions of empathy communication in medical settings are described by Pounds (2011), who overviews the verbal realization of empathy from the healthcare professionals' perspective and classifies it into two macro-categories: 1) Eliciting patients' feelings and views; 2) Responding to patients' cues. In this respect, Pounds et al. (2018) have demonstrated how support groups express and perceive empathy in online communication from the interlocutors' perspectives and given their expectations.

The issue of how parents deal with their children's needs and how they must struggle to gain support from the medical and professional community has been dealt with by Brewer (2018), who focuses on the sociological aspects related to (lack of) healthcare and socio-economic support as revealed by parents' – and above all mothers' – narratives. Little, if anything, has been written about the ways in which people narrate their experiences as *parents* dealing with their children's heart issues in order to share their experience and express empathy. To the best of my knowledge, their storytelling has never been properly analysed or investigated. This is relevant, as the analysis of such discourse mediates how people experience their children's congenital heart disease: the ways in which such illness is reported can facilitate or obstruct positive experiences. As Semino et al. (2018) underline, when language works well, it improves information, provisions, diagnoses and support. When it does not work, it creates, of course, misunderstandings, misdiagnoses, frustration, anxiety and disempowerment. It is therefore the aim of this paper to investigate how parents report their children's congenital heart disease with the purpose of providing support (and offering empathy) to other parents in a similar situation. More specifically, drawing on discourse analysis (Jones et al. 2015; Gee 2017), I carried out a corpus linguistics (Bondi – Scott 2010; Baker – McEnery 2015) investigation of the narratives of all the *heart children*'s parents found on healthtalk.org in order to detect how information, knowledge (and empathy) are deployed in parents' narratives in an attempt to help people to fill a cognitive and emotive gap. To this end, an analysis of the discursive patterns of the narratives found will be conducted, as will an examination of the verb that best expresses the parents' cognitive awareness (or lack of it) in their experience with their children with a congenital heart disease: *know*.

Healthtalk.org is a UK website managed by the Oxford-based charity DIPEx, created in order to help and reassure people and give them good advice related to any medical issues. In particular, the main purpose of healthtalk.org is:

- to support patients and their families in the decisions they have to take,
- to help healthcare professionals provide care to patients, and
- to facilitate patient-doctor communication.

The website offers free, reliable information about health issues (such as cancer, autism, neurological diseases, depression etc.) by sharing people's real-life experiences with the aim of helping people who are facing a similar situation and facilitating their decision making about health and treatment;

talking to friends and family; overcoming emotional and practical issues; dealing with any impact the disease may have on work or education.

In order to achieve that goal, this paper will proceed as follows: Section 2 describes the data, methodology and ethics applied in order to carry out the analysis of the findings explained in Section 3, in which data interpretation is also discussed. A conclusion is offered in Section 4.

The results seem to indicate that in these narratives the most recurrent patterns do not follow a traditional chronological order but are rather guided by people's emotional response to stress and trauma and, to a certain point, the societal expectations of good parenthood.

2. Data, methodological approach and ethics

As stated above, the aim of my analysis is to examine how support and knowledge to heart children's parents are communicated. In order to do that, I collected all available narratives from parents whose children are affected by a congenital heart disease which were uploaded to healthtalk.org by the Health Experiences Research Group at the University of Oxford and published by the DIPEx charity (available at: http://healthtalk.org/home). I was able to download 31 interviews and texts whose transcripts are available online (88,489 tokens; 4,100 types).

All downloaded narratives are indicated with the abbreviation CH for *child* followed by a number corresponding to the number of the text found at healthtalk.org, thus CH1, CH2, CH3 etc., which corresponds to the narrative about *child no. 1* family, *child no. 2* family, *child no. 3* family etc.

Consent to use the narratives was not sought from the parents because the terms and conditions of healthtalk.org state that all content published on its site is the sole property of DIPEx and its licensors and the reproduction of any part without written approval is prohibited. Consent to use the data for the purposes of this research was therefore sought from DIPEx, and was granted. Permission to download, use and archive the collected texts from healthtalk.org to carry out the present research was granted by the Health Experiences Research Group and by the DIPEx charity that runs the website.

The corpus thus collected was uploaded to Voyant tools (https://voyant-tools.org). Voyant tools (Sinclair – Rockwell 2016) is a Web-based text reading and analysis environment, an open source project (whose code is available through GitHub under a Creative Commons by Attribution licence), which has been elaborated by Stéfan Sinclair, McGill University and Geoffrey Rockwell, University of Alberta.

In order to carry out discourse analysis and corpus linguistics investigations, all texts were surveyed so as to allow greater contextualization of the content. If a video of an interview or a narrative was available, it was inspected.

All narratives were examined using discourse analysis (Jones et al. 2015; Gee 2017) and a corpus linguistics investigation (Bondi – Scott 2010; Baker – McEnery 2015). The study adopted a *corpus-based* approach (Tognini-Bonelli 2001; cf. also McEnery – Hardie 2012) which – differently from a *corpus-driven* study that explores new categories, frameworks or theories – focuses on existing linguistic categories, frameworks or theories to see whether they can be validated, refuted or refined by the corpus under investigation. Drawing on linguistic research on online health communication (see, for instance, Jones 2010 and Koteyko – Hunt 2016), and in particular digital storytelling (Page 2012), narratives were first examined to identify the existence of common discursive patterns in the construction of empathic discourse, and then scrutinized in more depth in relation to those aspects of *knowledge* via concordance lines, collocates and clusters to unveil the different functions that the verb *know* has in the studied context.

3. Results and discussion

As explained above, the 31 narratives collected from healthtalk.org resulted in a small corpus of 88,489 running words (4,100 types). Examination of all texts revealed a dominant pattern in the narratives: all of them start with statements reflecting the shock parents had at the news of their children's disease. Afterward occur the following components of content, which can occur at different points in the storyline depending on whether parents are recounting a chronological order of events or having flashbacks in their narratives:

- Coping with shock;
- Mothers who blame themselves;
- Looking for support;
- Lack of 'we';
- Parents sharing their experience;
- Winning children.

None of the narratives follow the storytelling framework of Labov and Waletzky (1967) and Labov (1997), which comprises *Abstract*, *Orientation* (comprising *Complication*, *Resolution*, *Evaluation*) and *Coda* stages. The *Abstract*, which prepares listeners for the text that follows and often orients them about the story's themes, is not present in the narratives but is provided via a website link. As to the *Orientation*, which sets the story's reference points (who, when, where, what, why), this is partially given by the DIPEx research team before each text: it is found as a heading before the narrative in the form of background information, such as the diagnosis, child's age at diagnosis, actual health and family situation. The core point of the narrative is represented by the *Complication action*, which in Labov's (1997) terms is the problem culminating in a crisis but differing from the above indicated frameworks. There is not always a *Resolution*, i.e. a way to resolve the crisis, although some children could be operated on (and so there was a *Resolution* for them), others may still need an intervention or be waiting for one (and two other children, unfortunately, died – in this latter case); we cannot see the crisis to be resolved with the children's death as a form of *Resolution*. The *Coda*, which signals the fact that the story is over, is marked as intended by Labov (1997): we do have a shift from past tense to present tense, and yet, instead of having a shift from specific participants to generic ones, we also have a shift from specific participants – the parents – to other specific participants – the heart children.

What is always present and overlapping in all stages is the *Evaluation* phase (Labov 1997). The *Evaluation* is a stage of storytelling which assigns significance to the story (Labov – Waletzky 1967; Labov 1997), as expressed in "the expression of incredulity, disbelief, apprehension about the events on the part of the narrator" (Rothery 1990: 203). It should normally occur between the *Complicating* action and the *Coda*, but in the narratives presented on healthtalk.org it is always found at the beginning of the narratives: it is actually the beginning of the parents' story. Indeed, in terms of *Evaluation*, for all parents the initial shock of discovering that their child has a congenital heart disease mainly means one thing: your child may die. It is with this idea that, after the initial shock, there is a second step, i.e. the re-organization of all family life through the steps indicated above – though not necessarily in that order.

In the following paragraphs, the dominant patterns found in all the narratives will be examined and analysed, and the most significative examples for each of them will be offered.

3.1 Evaluation stage: Shock

All narratives include a storytelling stage in which expressions of shock are revealed, as indicated in excerpts (1)–(5) below, each of them revealing a different degree of shock:

(1) It was very, very hard, it was one of the worst things that I've ever had to go through. At 20 weeks being told that your baby might not even survive, it's horrible. (CH8)

(2) As we say, we were told, weren't we? the last, last January [January 11th] that he had to have this operation and I, I nearly passed out. I just sat in that chair and I was, my head was spinning, I went cold, sweat down my back and I virtually did, virtually passed out I was, I was that close. And all I could hear was everything going on in the background and [my wife] being upset and I was just in a different world […] I was frightened and I was angry and scared. I thought he was going to die, because it's an operation. (CH17)

(3) It's denial really that, yeah, I think it's, I just didn't want to know that there was something wrong with her. (CH23)

(4) And it, it was bizarre, bizarre. I kept thinking 'This isn't really happening.' (CH21)

(5) I suppose, initially, your first reaction is 'Why? Why us? Why my daughter?' That, you know, I think that's a reaction that most people would have. You know, 'Why, why does it happen to us?' You know. And then, I think, I think you have to get over that feeling and we went through many things, it was just, I, I think it was shock. I think we were in so much shock to start with and we couldn't stop crying. None of us could stop crying and I think we were trying to put on a brave face for the children, my husband and I, and trying not to show them too much. But it was just such an emotional time, you know, and it was, it was just so hard to do that. (CH26)

The diagnosis is clearly shocking and difficult to accept. Indeed, parents physically do not want to accept it. In (2), for instance, the shock is so overwhelming that the father "virtually passed out". In (3) and (4), there is a "denial" of the whole situation, and in (5) a sense of impotence because of what is happening to them, to their daughter. As excerpt (5) indicates, the shock is about "why my daughter" but above all "why us? […] why does it happen to us?" The frustration is huge, as there is no answer. It is much bigger in the sense of the moral parenthood (cf. Austin 2016) and responsibility the narrator has: the presence of a congenital disease for which there is no culprit but the malformation itself ("they said that yeah [our daughter] had a hole in her heart" CH26) falls outside the range of parenthood's control over children's care: they can do nothing and yet it is their (social) responsibility to look after their children and take care of them.

3.2 Coping with the shock

Coping with the shock of the child's disease is not easy but it is necessary for the parents because they have to take decisions. Since this type of disease is not common, parents have an urgent desire to get informed. Parents gather information from the right channels – from doctors and specialists, as it should be, and as indicated in the examples below reported in (6) and (7):

(6) There is nobody else who can know better than the doctor. Be very well informed, be very well informed. Read, read, get information there is [the] Internet which has got loads of information. If you don't have access to that information there is so much information available in the libraries. But get information, read, ask questions […] So trust the doctors, go. (CH31)

(7) I think that what I'd say is try and get as much information as possible. Don't be afraid to ask simple questions. Try and make a list of all the questions you want to ask, don't be afraid to go back. (CH10)

Clearly, coping with the shock is not always easy, since the way people react is different. As one of the parents said, "I think we both coped in our own ways" (CH11). Furthermore, the emotional wave may be so devastating that people may miss what doctors say because they are more focused on their children than on medical information, as revealed in (8):

(8) They're great at doing what they're doing but that is your children and you, you've just got no idea of the emotions and everything that you feel from day one and if they explain things a little bit better and tell you about leaflets and help groups that you can go to I think it would help (CH18)

So, in this case, additional information about support groups or where to find information is essential.

All this seems to re-establish the control parents have over their socially-constructed notion of parenthood and the responsibility (Austin 2016) they have for their children: by getting information they can have knowledge about what is going on with their children so that they can protect them in terms of what types of decisions to take or whom to consult, even though they still must rely on doctors to get information, and eventually have their children operated on, on their hearts. In any case, it is parents whom doctors ask for legal consent, and by getting information parents acquire knowledge and hence power.

3.3 Mothers who blame themselves

A 'good' mother is a mother who conforms to societal expectations, i.e. one who is aware of her responsibility of protecting her child from harm and promoting health and development (Lupton 2011). Heart children are children who, because they have a congenital heart disease, do not develop well from a physical perspective, and their lives are at risk. Although it is the mother who most of the time realizes that something wrong is happening to her child, and it is thanks to her that the child can be treated, mothers think that their children's heart disease is their fault:

(9) And in that heartbeat, I thought, 'Oh my God,' you know. 'Does he think, what have I done wrong? Immediate guilt, that, that I'd done something wrong and then, did they think that I'd hurt her, dropped her or, it was some sort of… .' It was this awful panic. (CH21)

(10) I did go through a stage of thinking it was all my fault and I think everybody does. … And then you start to think 'Well, it's my fault. I've done something wrong. I shouldn't have done this, I shouldn't have done that,' and the hospital assures me that there's nothing that causes it. (CH14)

As can be seen in excerpt (9), the mother's main worry is that her husband believes she has done something wrong, that she is not a good mother. Similarly, in (10), it is the hospital staff who assure the mother it was not her fault, so motherhood has not been compromised. This awareness of others' judgemental attitudes with regard to the mother's caring capacities is reflected in the irrational guilt mothers feel for not having been able to protect their children from a congenital disease, which results in an impossibility to conform to societal expectations (Lupton 2011), as explicitly indicated in (11) below, when the mother explains that she decided not to bond with her baby out of fear, and this was "a terrible situation to be in" (my emphasis):

(11) I didn't really bond with my baby at all before he was born because I was afraid to, because I was afraid that I was going to lose him. So, I just didn't want to feel that I was getting too attached to him. **Which is a terrible, a terrible situation to be in.** (CH11)

3.4 Looking for support

In these shocking moments, when parents are afraid for their child's life, when they believe they are not responsible parents and 'good' mothers, and thus think they do not conform to societal expectations, their desire to find support grows. They want to be reassured that everything will be all right, as revealed in (12) and (13):

(12) I just wanted somebody to tell me that she was going to be all, all better, and that she was going to have the surgery tomorrow and when she came out that she'd be absolutely fine and healthy. And that'll be the end of it. (CH23)

(13) All you want is for the doctor or the nurse to say to you, 'Everything's going to be all right. Your baby's going to live and the operation's going to be successful.' And they can't say that. (CH8)

The type of support they are looking for is psychological, from the professionals. Indeed, they would like to find "someone", but not simply anyone, rather a "doctor" or a "nurse", as indicated in (13), who can say that "everything's going to be all right". Yet, according to Fisher (1995) and Sinclair (1997), while nurses are trained to be carers, doctors are trained to be "curers" (Crowe – Brugha 2018: 155). What emerges again is *Evaluation* in the final sentence, "And they can't say that", in (13). This is not so much something said because doctors and nurses need detachment from the family (cf. Crowe and Brugha 2018) but because specialists need to tailor information in terms of what they know and what they do not know – which is the case here.

Parents actually find the emotional and psychological support they need from Heart Associations, liaison nurses and other parents, as indicated in the excerpts below:

(14) So, I do remember people being sympathetic and supportive and appreciating the fact that we were completely unprepared for this. We had no knowledge. And they might have been bombarding me with

a load of information, but I just cannot remember. I just, I just couldn’t think straight. (CH9)

(15) I think the most helpful people at that stage were probably the Children’s Heart Foundation who were able to send us quite, kind of, clear statistics and put us in touch with other parents, and the cardiac liaison nurse as well, you know, gave [us] telephone numbers of other parents. (CH10)

(16) The British Heart Foundation, they gave us some, an absolutely fantastic booklet that explains everything that you can think of and it was then that we read the symptoms. (CH18)

The support is not simply medical: emotions here find the right empathic ‘container’, as revealed in (16), where the booklet given to parents was “absolutely fantastic”. Elsewhere the “staff were absolutely tremendous” (CH26). The presence of the intensifier *absolutely* and the evaluative adjectives *fantastic* or *tremendous* demonstrates what in their opinion has gone exceptionally beyond their expectations and probably reassured them to a certain extent.

3.5 Lack of ‘we’

Together with the desire for support, a sense of isolation grows in and between parents. Both parents are concentrated on their child, who has become the only centre and scope of their life, but such a situation may result in two different conditions.

(17) You, you become selfish in the sense that as a husband and a wife I always put Daniel in front of [my wife]. And vice versa, [my wife] would put Daniel in front of me. And some people could say, ‘Well what’s wrong with that? You’re child’s… is absolutely priority’. Yes, but you then build a wall between sets of parents and you need to be together rather than two individuals coping with it. So, you should still take time out to socialise with your friends. You should support each other as well as obviously your family side. Encourage each other to, you know, still go out, go to the pub, go the match, do the normal routines of a married couple. But never ever lose sight of the fact that as parents you were here before the children and when the children came on board. (CH8)

In excerpt (17), above, parents seem to create a wall between themselves as a couple, which may slowly destroy the couple itself. The narrator is no longer thinking about an inclusive *we*, as the example below reveals:

(18) We weren't really sharing and talking about what we were feeling, we were just sort of dealing with it on a day to day basis and not really discussing it, I think I didn't realise what an impact it was making on him and I found out that my husband was actually taking a 'condolence' and talking about it with a colleague at work whereas he, he should have really been talking about it between the two of us. So it was both of our faults really. So it really has made an impact on my marriage. (CH26)

The stress of coping with the situation may have an impact on their life as a couple. In other cases, the narrator thinks about a *we* which is exclusive in terms of socialization: parents simply forget about the world outside the hospital:

(19) When you're in hospital you totally forget about the outside world. (CH20)

Priorities are different, their child is the centre of the world and this is what responsible parenthood requires (Austin 2016).

3.6 Parents sharing their experience

Pounds et al. (2018: 37) have underlined how, in online support groups, expressions of empathetic communication acts can be found, through which people share similar experiences and feelings without any form of advice, such as "I know what it's like being ill." Similar expressions seem to be common in the texts forming my corpus:

(20) This baby's here it, it would help other children. (CH8)

(21) I feel that there was a reason that my daughter had this heart defect. I don't know why, I don't know whether, you know, in later life that she'll go on to be a support to somebody else who's had a heart disorder or what. I really don't know. (CH26)

(22) And now if I ever see a mother who's obviously in that state I try to reassure her and say, 'Look, you know, here's my son, it'll be fine, you'll be OK.' Because it is just all overwhelming and it just made it

> so much easier to know the routine the next time one went back and what was going to happen. And then after a while it just becomes a pattern, it's very reassuring. (CH24)

Obviously, these expressions resemble what parents hoped to hear when they came to know their child had a congenital heart disease. This also acknowledges other parent's feelings, while creating empathy (Pounds 2011) by providing implicit and mitigated forms of advice, clearly involving consideration of others' needs (cf. Locher – Hoffmann 2006).

3.7 Winning children

The parents' narratives take an unexpected turn: from descriptions of their feelings, of their experience, of their shock and how they had to cope with all of this, they eventually turn to their child. They never report their child's feelings, whether the child is afraid about what is happening or not. No words are spoken about that. When parents turn to speak about their children, we are at the end of their narrative. The recurrent pattern involved in this part is the child's showing off of the scar. The scar is proudly exhibited as a trophy, as if the child wants to demonstrate his/her own power and control over their heart disease:

(23) My son was there proudly showing his scar off to everybody. [laughs] He's not, not ashamed of his scar, he shows it off. (CH9)

(24) And they said, 'Show them your scar,' and he went, 'Hmm, look at this.' And he was so proud, you know, he was showing everybody his scar. (CH20)

(25) He's kept them in a bottle and he proudly shows people what his stitches look like. (CH24)

This is the *coda* (Labov 1997), indicating that the story is over.

3.8 Corpus linguistics analysis. *Know*

The analysis of the parents' narratives has revealed some dominant recurrent patterns, one of which is the necessity of coping with the shock and getting control over it in order to re-establish parenthood. This is partially achieved by getting information in order to fill the gap caused by the ignorance parents have about the heart disease their child is suffering from. The quantitative analysis of the corpus with Voyant tools seems to confirm this. Indeed, among the top ten most frequent words in the corpus, *know* is the most frequent, as can be seen in Table 1, below, (1009 occurrences):

Table 1. Breakdown of the top 10 most frequent words

Term	Raw Frequency	Relative Frequency	Distribution
know	1009	0.011402547	0.011402547
just	788	0.0089050615	0.0089050615
think	562	0.006351072	0.006351072
it’s	471	0.0053226952	0.0053226952
really	470	0.0053113946	0.0053113946
going	367	0.004147408	0.004147408
father	363	0.004102205	0.004102205
sort	362	0.004090904	0.004090904
mother	357	0.0040344	0.0040344
like	351	0.0039665946	0.0039665946

The verb *to know* is a stative private verb, indicating an intellectual state which can only subjectively be verified (Quirk et al. 1985: 202). It is a cognitive verb which can introduce indirect statements with *that*-clauses. When used in this way, the speaker attributes to the sentence a high degree of epistemic certainty about the state of affairs expressed in the *that*-clause (cf. Cappelli 2007: 156).

A breakdown of the use of *know* reveals that the verb is mainly employed with the following:

Table 2. Breakdown of the different functions of know

Use		Occurrences
Comment clauses (“you know”)		717
Knowledge	Evidentials (“I / we know that”)	154
	Lack of knowledge (“X don’t / doesn’t know”)	112
Negative expression: denial (“X do / does not want to know”)		18
Feel (“I know that / it ”)		8
	TOTAL	1009

As can be seen in Table 2 above, *know* is mainly used in comment clauses (717 occurrences) and evidential expressions (154 occurrences), but also in expressions related to lack of knowledge (112 occurrences). Comment clauses are parenthetical disjuncts that express the speaker's comment on the matrix clause (my emphasis, here and there below):

(26) I think it, if it is an antenatal diagnosis what my emotions were at first were I didn't want to know. I didn't want to have been told this piece of information because that then gave me a decision to make that I didn't want to have to make but with hindsight that antenatal diagnosis actually saved his life. If he hadn't had that diagnosis he would have been born at a different hospital where they didn't have any paediatric support at all. So, **you know**, it just would have been horrible and because he was, he was that unstable in an intensive care environment without any support at all. (CH3)

These types of comment clauses realised with "you know" are stereotyped in the sense that they imply certainty on the speaker's part and at the same time require the hearer's attention *and* agreement (cf. Quirk et al. 1985: 1114-1115). For instance, in (26) above, the speaker is drawing the hearer's attention to the fact that although she for a moment would have preferred not to be told about her baby's congenital disease during her pregnancy, the antenatal diagnosis was nevertheless important because it saved her child's life. If she had not known, "it would just have been horrible" and the comment "you know" underlines the severity of the baby's condition and the correctness of the mother's decision. Had she not known that, it would have been terrible, and the baby would have died. Good motherhood (Austin 2016) has been maintained. Even when parents do not act, "you know" becomes a comment for agreement sharing:

(27) None of us could stop crying and I think we were trying to put on a brave face for the children, my husband and I, and trying not to show them too much. But it was just such an emotional time, **you know**, and it was, it was just so hard to do that. (CH26)

Epistemic certainty is also expressed when *know* realises evidentiality. Evidentiality is a linguistic phenomenon by means of which the speaker/writer provides the source of information on which a claim is based; such sources may be seen, heard, inferred from indirect evidence or learned from third persons (Aikhenvald 2004). In all but one of the cases found in my corpus, the source of evidence is direct (the parents, the literal authors of the narrative); in one case it is indirect (the doctors whose text is reported by the parents), as can be seen in the excerpts below (cf. Willett 1988):

(28) I know that she’s going to need follow up and **I know that** she does still have a small lesion/ hole there so she’s going to have to, always have to be careful. (CH12)

(29) For Thomas **we do know that** there’s a possibility that he may need a heart transplant in the future, if he doesn’t thrive. (CH2)

(30) **I know that** when she has to have more treatment he’s going to be a help […] Alex is three, so for 3 years **I didn’t know** that information was there. So, it was just by chance that I actually found out. (CH4)

(31) **We didn’t know** all the help we could get until the social worker had been in touch with us. (CH18)

(32) **They know that** she does have a heart history as well. (CH12)

Whenever evidentiality is used to indicate the type of knowledge parents have, it is to show that they are aware of their child’s health condition and future treatment, so they know what to do. These expressions are always in the present tense, in contrast with the negative form in the past “didn’t know”, which clearly indicates a lack of knowledge: they did not have any information about medical issues and the story they are about to tell concerns the incredible fact that they managed to get information by chance, as in (30) and in (31). Doctors, in contrast, know that children “have a heart history”: they are professionals and have information, as (32) reveals.

When the subject of *know* is “they” referring to doctors, the complement introduced by *know* is a *wh*-clause:

(33) They thought that, they think what caused it is, that it was actually irritating the heart so his blood pressure just started to, to crash and **they didn’t know what** was causing it. (CH7)

(34) They couldn’t decide why Luke was deteriorating as rapidly as he did and they were discussing him when he actually arrested, by which time it was too late. But **they didn’t know why** he was deteriorating. (CH19)

The use of *wh*-clauses implies a lack of knowledge on the speaker’s part (Quirk et al. 1985: 1184) which is indirectly expressed through the doctors’ inability to explain the reasons for the child’s heart failure. If this is so, the blame cannot be put on the parents, and good parenthood is in a way maintained.

There are a number of instances in which *know* in the negative form expresses a form of denial:

(35) I wish I'd had a **blissful ignorant pregnancy** and really been able to get attached to my baby before he was born. (CH02)

Ignorance is in these cases felt as *blissful* because, for mothers, not knowing would not only mean loving their children without any worries but also not panicking, as excerpt (36) shows:

(36) Right, I'll face intensive care when I have to. It's just another thing that, if I see it now, it might freak me out, so **I don't want to know**. (CH17)

In a few cases, *know* seems to indicate the parents' sixth sense when they come to predict what will happen to their children:

(37) You *know*, '**I just know**, I have a good feeling.' You *know*, I think he's, he's, *that's kind of been our way of coping*. (CH25)

Looking after a heart child does not only mean being physically close to their child at all times to provide comfort and keep checking. This proximity creates an emotional bond by means of which mothers become the information brokers of their children in the emotional interdependence which is being created between them (Young et al. 2002).

4. Conclusions

In this paper I have tried to describe the narratives of parents who have heart children and who want to share their experiences, as found on healthtalk.org, in order to detect how information, knowledge (and empathy) are deployed with the aim of helping other people in a similar situation to fill a cognitive and emotive gap. The investigation has been carried out by detecting the most recurrent discursive patterns of the narratives, followed by an analysis of the most frequently used verb that best expresses the parents' cognitive awareness (or lack of it) in their experience with their children with a congenital heart disease: *know*.

Exploration of the narrative pattern has shown that the traditional structure of narratives, as presented by Labov and Waletzky (1967) and

Labov (1997), is not followed, since the story parents tell is constructed in a new unexplored way. The discourses in these self-narratives follow an emotional flow which is different from story to story but presents a recurrent thread. This does not follow a precise chronological order, as flash-backs and emotions prevail in all the stories, but the main features in them are the following:

- Representation of shock;
- Coping with shock;
- Mothers blaming themselves;
- Looking for support;
- Lack of 'we';
- Parents sharing their experience;
- Winning children.

The leitmotif underpinning all these features is the question of parenthood: good parents are those who take care of and look after their children. This is why, after the initial shock, they all try to cope with it in order to reorganize their life – the best way to do so is *to know*: having knowledge grants them access to information and the possibility to make the right choice, which is what is required of good parents. Mothers feel they have a further moral responsibility: since they have not been able to protect their child, they feel morally responsible for this – and blame themselves. The proximity they create with their child, both physical and psychological, allows them to re-establish their social order and re-acquire the position of good mothers: they do what they think good mothers should do.

How parents cope with shock differs from person to person, but, generally, they cope with it by seeking support and information. In this quest for support, they also seclude themselves from the world, and even from each other, in order to focus on their heart child. Once the order is restored, the parents' narrative grants empathetic support to other parents in a similar situation and ends by describing the winning child showing off his/her scar.

The analysis of the most frequently used verb, *know*, carried out with Voyant, reflects in a way the described narratives above: in a comment clause, *know* is used when parents look for the listener's agreement; when it is used to indicate evidence, *know* is employed to show the awareness parents have as to their child's medical condition; in the negative form, the lack of knowledge they have is always expressed in the past, when they were in turmoil due to the shock and *did not know* and had no control, or, where the subject of the negative is 'the doctors', such a lack of knowledge is imputable to others, not to them – and in this case, good parenthood is preserved. In the few cases in which parents prefer *not to know*, this occurs because not knowing allows them not to panic. And last but not least, parents *know* in a sort of *sixth sense* what will or will not happen to their child – which is exactly what society requires for good parenthood.

Undoubtedly, trauma resists language. Emotions must be accommodated, and a lot remains unsaid or is not always or fully reported. Conversely, people in similar situations may appreciate knowledge derived from the narratives reported by parents who previously had similar difficult experiences. For them, reading about and listening to others' experiences may be of greater empathetic value.

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