Drawing the Line between Sick and Healthy: Normality Constructions in Health Communication Contexts

Mats Landqvist & Zoe Nikolaidou

To cite this article: Mats Landqvist & Zoe Nikolaidou (2019): Drawing the Line between Sick and Healthy: Normality Constructions in Health Communication Contexts, Health Communication, DOI: 10.1080/10410236.2019.1652389

To link to this article: https://doi.org/10.1080/10410236.2019.1652389

© 2019 The Author(s). Published with license by Taylor & Francis Group, LLC

Published online: 14 Aug 2019.

Submit your article to this journal

Article views: 46

View related articles

View Crossmark data
Drawing the Line between Sick and Healthy: Normality Constructions in Health Communication Contexts

Mats Landqvist and Zoe Nikolaidou
School of Culture and Education, Södertörn University

ABSTRACT
In this paper we examine how traditional views of normality are negotiated, endorsed and resisted when talking about children with heart defects. Having as a starting point an ethnographic project that aimed to study knowledge construction when being pregnant or having a child with a heart defect, we focus on argumentation put forward by clinicians and parents in order to understand the forms that normality takes in relation to children’s health and illness and the way that it is constructed argumentatively and linguistically. More specifically, we draw data from recorded doctor-patient consultations, ethnographic interviews and entries from family blogs and forums and focus on those instances where normality is negotiated as a means of providing a medical consultation or of taking and motivating decisions about the child’s health and everyday life. The analysis is conducted by identifying content and logical topics in the data and showing how constructions of normality and alternative conceptions are constructed in discourse. Discourses are additionally related to discursive, semiotic framing and the realization of norms. Our results highlight a duality that is being painted both in the clinicians and in the parents’ discourse when negotiating the illness and the accompanying risks in the child’s everyday life. Some of the traditional norms being re-constructed and re-negotiated in the data are those of stigmatization, diversity, responsibility and freedom of choice.

Introduction

In situations where people discuss their health problems different points of view are made relevant of what or who is to be considered healthy or sick, and in this way how to draw the line between healthy and unhealthy conditions. In this distinction, a meeting take place between norm critical perspectives, advice from the medical profession and people’s real experiences of living with disease, concepts of illness and other discourses, that are all dimensionalized and problematized in intricate ways, as different contexts draw their lines around normality differently. In our research project on health literacy, we have investigated online forums, consultation talks with physicians, medical websites and social media and have come across many examples of normalization made by doctors, parents to children with congenital heart disease and others. In this article, we take an interest in these examples and analyze normality from the viewpoint of how it is constructed in dialog and tropes. This means that we investigate how the view of the normal is made visible and re-emerges in different contexts in which issues of children’s health are discussed, for instance in conversations between caregiver and parent, or in everyday social situations where a child’s disability or disease forms the topic.

A point of departure is that the normality of the body can be a matter of negotiation, meaning that conceptions of health(iness) are often implicit and self-evident, and in situations when good health is not the case, a negotiation takes place concerning what is included in good health or where to draw the line to disease. The need to normalize will be central for parents to “heart children” because normality is part of several choices, not only in one’s own self-conception, but also in health care practices, in which established opinions of what is to be seen as normal decide the level of care and treatment. Norms and norm perceptions can be part of a constant reconstruction of the social structures governing our perceptions of what and who is normal, or the opposite, who is well, unwell, normal, deviant and so on. However, such presupposed dichotomies may also be false.

Key concepts for this study are norms and normality. A well-known definition of norm and normality is taken from Foucault (1995), who claims that judges of normality are omnipresent, and that those judgments create the “universal reign of normality” (p. 304). Accordingly, norms and conceptions of normality regulate behavior and actions, including speech acts, interplaying with social contexts. For example, persons with disabilities are shown to consider the potential outcome of revealing information about their disability (Braithwaite, 1991). They tend to avoid that their disability is perceived as a sickness and they try to keep their disability from being the sole focus. Goffman (1963) discusses stigma as the cause of a spoiled social identity, the identity of the discredited and the unwanted. He argues that stigma can be seen from a double perspective, depending on whether what is stigmatized assumes that other people are aware of
their difference and are in this case rendered discredited, or that the difference is not visible to other people and thus be rendered discreditable. However, we see a need to focus on how different norms may be present at the same time, due to orders of discourse (Foucault, 1991), meetings of perspectives and conflicts between opinions, points of view etc. In addition, it would be relevant also to include norms governing health care, the medical profession and anatomical knowledge, all of which are potential sources of norms regulating patients’ social life. We identify norms that seem to be realized as dominant, pre-conceived, frequent and widespread. These are different from alternative norms, i.e. resistance to and re-construction of the traditional construction of normality, often due to parents’ own experience or the perception of other conflicting norms, such as free choices and neo-liberal discourse. Norms may also be conceptualized as expert norms, either attributed to professionals or to laymen, so called ‘layman expertise’ (Bellander & Landqvist, 2019; Prior, 2003).

Another key concept is argumentation, and we adhere to a classical rhetorical take on this. Content topics are the main themes and issues at hand in, for example, a conversation between doctor and patient, while common topics are logical bearings on the discussion, such as comparison, causality, quantity, quality, etc. To some degree we also include fallacies in the analysis, mainly simplification, over-generalization, false dilemmas. A third key concept is the discursive framing of norms. Framings of relevance here can be many, such as antithetical reasoning, choice of verbal processes, reference to actors, mitigation, modality and so on.

Norms governing health/sick can emanate from a general agreement of what is dangerous, okay, valuable or neutral – definitions however depending on the context. A norm may be something that “is managed, perceived, utilized” in a certain domain, with different relevance for how it is expressed (Green, 2009). This means that different, also contradictory, norms may be valid at the same time, even for the same individual. Such variation can be associated with which norm appears to be working validly in a specific context. A similar way to defining norms about healthy/sick is that it works “as control, resistance, embracing, and enduring” (Launiala & Honkasalo, 2007). The norm is not only prominent and valid in a context, but it also governs attitudes and values on a deeper level. This way of understanding norms indicates that an individual’s action in a health situation depends on what standards have been identified as sustainable and relevant. This is not surprising, but it is essential to get a better understanding of how this norm perception as a means of control affects the choices made by parents and healthcare professionals together, and not least of what decisions appear to be sensible for parents in the daily care of children. Conceptually, this might be a determination: How does the perception of norms affect their own choices, and how can you predict these choices? In order to make such predictions, a study also needs to include the relative in the norm application: What is perceived as more/less normal than anything else? This relativity, in turn, depends on the degree of social considerations that an individual need to take into account, that is, what norm deviations mean for the contact with the environment. It further depends on attitudes, basic values and flexibility, the role that previous experience and surroundings play, as well as when a certain norm becomes important enough to be crucial.

**Aim of the study and research questions**

The aim of this article is to understand how the view of the normal is made visible and re-emerges in different contexts. In order to answer this question, we analyze data collected from different sources and contexts regarding how normality is constructed discursively. With such an analysis we hope to find important clues as to how parents reason in relation to advice from experts, to medical information of different kinds, and to demands arising in everyday social life; and how these sources of norms and discourse may be in conflict. In order to achieve our aim, we pinpoint different ways of normalizing a negative health condition in interaction with others.

The research questions underlying the study are the following:

1. What norms about sickness and health are reconstructed by clinicians and parents in interaction?
2. How are these norms re-negotiated in social contexts?
   a. By employing logical and content topics?
   b. By employing linguistic resources?

**Norms in healthcare practices**

Normalization discourse in health care is an extension of dominant ideologies at a given socio-historic moment and in a given cultural place. Legitimation ideologies can be traced in medical experts’ professional practice in an attempt to reinforce and establish them. The same ideologies seem often to be shared and reproduced by patients and laymen experts, since both professionals and patients operate within political and economic contexts which shape the practices promoted as best for the patients at a given time. In a study of normalization practices in families with children who suffer from chronic illness, Anderton, Elfert, and Lai (1989) ask the question whether cultural and ethnic differences play a decisive role in illness management and in the conceptualization of normality. Their study shows that economic and other factors of material existence, such as level of education in the family, to a great extent shaped the way families dealt with their child’s chronic illness, the level of compliance to the experts’ advice and the direction given to normalization practices. Normalization in terms of parenting choices was associated either with the child’s immediate situation and quality of life (when the parents belonged to an educated, upper middle class) or with the child’s future life in terms of employment, marginalization and economic survival (when the parents belonged to a working, immigrant social class). Health literacy and normalization practices are today defined even more by socioeconomic factors, not least in relation to access to new technologies.
Normalization practices in the Western world are heavily shaped by the postcolonial discourse of individualism. As opposed to collective cultural frameworks where one’s bonds to family or clan are the cornerstone of the societal structure, individualism gives priority to individual needs and goals and places them at the center of human action. Within the context of this neoliberal discourse, the concept of the family has been transformed and expanded (Bäck-Wiklund & Bergsten, 1997), and parenthood has become a rather complex practice formed equally by freedom of choice and responsibility. In a comparative study of the sociohistorical discourses shaping parenthood in the last 150 years, Westberg (2016) shows that postmodern parenthood is strongly regulated by discourses that focus on the child and the parents’ individual needs. Being a parent on these premises, when not following commonly decided or socially imposed rules about how to be a parent and instead being responsible for continuously deciding what is best for one’s individual child, results in being caught in a constant state of risk managing situations followed by anxiety and concern. Westberg argues that, from a diachronic perspective, risk management and anxiety related to parenthood are significantly more common in the 2010s, and connects this with Gidden’s (1991) argued sense of reflexivity in relation to postmodernism, that is the individual’s tendency to observe their own practices and reflect upon them.

Along with a move toward neo-liberal governance (Fairclough, 2000) has come an increased construction of children as the private responsibility of parents (Wall, 2004), reducing state responsibility for collective social problems. This move may suggest self-governance and individual responsibility also toward disabled children, whether this means constructing them as in need of special attention or as any other child. For instance, we have shown, in earlier studies within this project, that parents of children with heart conditions take great responsibility for their child’s health and actively seek knowledge that will help them take critical decisions and provide care (e.g. Bellander & Landqvist, 2019; Nikolaidou & Bellander, 2019). Similarly, in a study relating difficulties in parenthood to shame, Hanell (2007) shows how parents can adopt a deficit view of their parental skills when not abiding by ideological norms related to breastfeeding. In all these studies, we deal with strong instances of governmentality where the involved individuals attempt to self-regulate their conduct as parents and align it with dominant perceptions of normality of parenthood and childcare.

A discourse that sees health and wellness as a lifestyle is also relevant here. Individual responsibility promotes self-care as a practice sought by patients, but also encouraged by the Western biomedical community. Individuality, naturalism, objectivity and rationalism are positive values encouraged in the pursuit of good health (Donnelly & Long, 2003), and it is an individual’s moral responsibility to make sure they abide by them in their everyday life. The wellness discourse is above all a moral discourse, a norm that wants people to strive for being healthy for more reasons than just bodily results (Conrad, 1994). More importantly, a healthy lifestyle results in an improved sense of self and in a feeling of being an accomplished and productive community member.

Another traditionally dominant discourse encountered in the context of health and healthcare is the construction of illness as a sin or a contamination (see Lupton & Chapman, 1995, for metaphors used to describe sickness). Being ill means being expensive and consequently a burden, something that needs to be taken care of in order for the rest of society to function properly. Being ill is seen as the result of the individual’s own wrongdoing, something they can be accused of for not doing things the right way, as the rest of the healthy population has done. People who suffer from chronic illness are often at the receiving end of this anathema and result in identifying with this state of risk managing situations followed by anxiety and concern. The continuing need to explain one’s incapacies may result in the construction of negative self-narrative” and thus be excluded from social interactions. A coping mechanism here can often be to struggle for normality, to cover one’s illness and to present a normal life at all costs (Sanderson, Calnan, Morris, Richards, & Hewlett, 2011). This deficit view is challenged not least by health promotion attempts to address it, but the stigmatization seems often to persist despite such attempts.

Discursively constructing health-related risks is a common way of maintaining control over sick bodies. Engaging in practices of risk assessment can, therefore, be seen as an act of resistance to major hegemonic risk discourses such as that of the stigmatized identity. An example of this kind of resistance is discussed by Fage-Butler (2017), who examines risk discourses regarding birth settings and highlights the strategies used by pregnant mothers to challenge traditional, normalized discourses on childbirth, to reject the deficit view imposed on them as pregnant women and instead promote the discourse of home birth as a moral choice.

Re-appropriating one’s illness is also an act of resistance to the persistent deficit discourse that wants patients to feel shame and take responsibility for their illness. Normalization practices here take a different role, as they are drawn upon by patients not as a result of suppression and alignment with dominant discourses, but as a means of coping and reconstituting their identities as chronic ill individuals. Sanderson et al. (2011) describe appropriation as resetting normality, trying to include one’s illness in normal life or keeping the illness as separate from normal life. Concrete strategies described here are increasing one’s tolerance of pain, finding benefits with the illness (such as closer connection to family and personal growth) and fluctuating symptoms. Re-appropriating an illness and resetting normality involves healing, reconciling with one’s body, accepting becoming a person and not just a diagnosis, and it is a conscious or unconscious act of resistance to the stigmatization of the chronically ill.

Material and methods

The data collected for this study is rich and diverse in nature. We place our study in the methodological field of linguistic ethnography, where language use is studied in situated contexts and researchers make use of ethnographic methods in order to decipher these contexts (Rampton, 2007). Our data is rich and diverse in nature, focusing on sets of practices and communication chains rather than on isolated texts and interaction.
We have in total 43 sets of pregnant couples and parents who have provided us with diverse data, depending on the point in time during their pregnancy or parenthood. All participants have had a fetus or a child that had been diagnosed with a heart defect. We have 19 recorded consultations with cardiologists: ten recordings are of the first visits of pregnant couples in order to receive a diagnosis, four recordings are of return visits during the pregnancy and five recordings are of parents’ medical appointments where an examination of the sick child takes place. We have conducted in-depth narrative interviews with 12 of these pregnant couples and parents, as well as eight interviews of the same kind with parents that we have not recorded in consultation meetings. In these interviews, we have asked the parents to freely describe their own and their child’s health journey, from the time they received the diagnosis until the time of the interview. We asked follow-up questions in relation to the way they looked for information and built up knowledge and the things they have learned during this process. We have also conducted an in-depth interview with the three cardiologists who took part in the recorded consultations, and we have asked them questions about the purpose and the nature of the consultation sessions, as well as questions about their approaches to communicating diagnosis and treatment to the pregnant couples.

An additional method for meeting parents is to read blogs. We have in our data 14 parent blogs with a focus on being pregnant with and having a child with a heart defect. We have contacted and interviewed five of these bloggers. These interviews are similar to the ones with any other participants regards their open nature and the call for narratives, but an additional focus here has been the blogs, the functions they fulfill, the process of writing, its affordances and restrictions. Similar to the blog material, we have also collected data from family forums and other social media, such as Facebook and Instagram. Finally, we have collected texts that became relevant for the parents during their and their child’s health journey. These texts are anything from heart drawings to books and leaflets with information about heart defects. The diverse nature of our material has contributed to a deep understanding of health literacy practices from different perspectives. We have been able to trace communicative chains and examine how they unfold, but also to talk to the people involved in these chains and examine how they experience these communicative events differently, depending on their role and on their aims. Thus the different kinds of data here was collected as a means of deepening our analysis as to what it means to engage in health literacy practices.

Another aspect of our analytical framing is common, logical topics in the data (Wodak & Meyer, 2001). A causal connection, a comparison or a quantification, for instance, made by participants may be present in several kinds of discourse. We identity them through all situations and texts and relate them to discursive, semiotic framing and the realization of norms. In this way, we hope to collect clues as to how both constructions of normality and alternative conceptions are constructed in discourse. This applies regardless of what norm is viewed as dominant in a context. Since norms are socially constructed, we take a particular interest in the relevance of the semiotic resources both in maintaining norms and challenging them. This means that discursive strategies affect how a norm is enforced, dismantled or transformed (Wodak, 2004). However, the analysis will not only focus on what is constructed regarding topics (Zagar, 2010), but also how this is done in terms of logical reasoning, connections and arguments, etc. The analysis of topics in our take departs from the notion that common topics are crucial for how an analysis can be widely applicable and provide results crossing context borders and being possible to generalize to other cases. Logical topics can also include fallacies. Fallacies relevant to this analysis are primarily false dichotomies. To underscore linguistic relevance even more, the ambition is to map semiotic resources, especially those indicating recurrent patterns of argumentation. Naturally, this makes the analysis two-fold: a certain pattern may be how comparisons are made in general, and at the same time this argumentation practice may also indicate how this is applied to health normality specifically.

In sum, norms are indicated by the content of discourse, such as with words depicting the ordinariness of a disease, its frequency, patients’ normal accomplishment and so on, showing different ways of normalizing and de-normalizing semantically. This calls for a systematic analysis of key words indicating the underlying norm. Arguments are mainly analyzed as formal textual features, i.e. words indicating textual connections, indicating discursive strategies. This calls for systematic analysis of logical markers in text.

Results

In the sections that follow, we draw examples from our data in order to discuss constructions of normality in cases where the heart defect is rather mild. We focus on the norms that are being constructed when talking about children with heart defects, on the argumentative strategies employed in order to resonate in relation to the norm, and on the way that these norms are linguistically constructed. We start by focusing on argumentation put forward by doctors when consulting pregnant couples and then go on to look closer at parents’ argumentation while being interviewed by us or in their blogs and entries in family forums.

Clinicians negotiating norms

In this first part of the analysis we take as a starting point the pregnant couples’ first consultation session with the cardiologist and focus on the doctor’s argumentation practices. The consultation sessions are rather special in nature, as the patient is an unborn embryo, and there are many issues at stake when consulting the parents. It immediately becomes clear that the structure and the content of the consultations are not of the traditional doctor-patient kind. The cardiologist’s task is not only to give and explain diagnosis and discuss treatment. A long part of the discussion that takes place circles around questions of the child’s future life quality, i.e. expectations in terms of physical capacity and mental abilities, comparisons with other children, etc. In our interviews with them, the cardiologists have expressed an awareness that this is a very unusual and sensitive session as the patient is technically a fetus, and the aim with the consultation is initially
not to treat the defect but to inform the parents. The consultation could potentially lead to a termination of the pregnancy, which in theory does not go hand in hand with the doctor’s traditional role of treating a patient. This is a rather new situation for the cardiologists, as the advancement of medical technologies has only recently allowed for a heart defect diagnosis already in the fetal period. This technological advancement makes it possible to give parents an early choice and the responsibility of making a decision. An additional aspect that seems to influence the nature of the consultation session is a movement of reform with an emphasis on diversity, in this case diversity when it comes to bodies and minds. A sick or disabled child should be offered the possibility of an independent, economically viable and “normal” life. The doctors’ and the parents’ task (in case they decide to proceed with the pregnancy) is to make sure to create the conditions for such a possibility.

This rather new and complex contextual landscape cannot be ignored by the doctors in the consultation sessions with the parents. On the contrary, the cardiologists in our data seem to take these aspects into serious consideration and therefore embed in their medical discourse questions of normality and life quality when giving the diagnosis. As a result of the above-mentioned issues, the consequences of the congenital heart disease are related by the doctors with a large degree of relativizing of the anticipated problems. The doctors compare with other children but avoid open gradings or evaluation. This is accomplished by a questioning of assumed general perceptions of children with heart disease, for instance in the necessity of having a high physical ability. In this way, the doctor can resist dominant discourses and common norm perceptions of healthiness and sickness.

The (re)construction of normality in the first example from a conversation between a pregnant couple and a children’s cardiologist seems to be based on the assumption that parents always expect a child who can achieve maximally in sport. By the relativizing of the necessity of being a physical high achiever, it seems as those expectations can be problematized and nuanced, and in the end neutralized.

Example 1

(D = doctor, F = father)

D: most of the children they feel good, most of the children develop the normal way they have, if we test this child that’s coming, it will definitely have reduced performance capacity and it will have reduced endurance, but I cannot answer how much reduced, most of the children if you think about yourselves, when did you last use your maximum work capacity, when did you reach your max?
F: no, it was maybe in the army
D: it was then at some point
F: (laughs)
D: it was maybe in the army, it makes sense if we were to test for maximum work capacity, it is lower than the same child or than the same individual who has a healthy heart
F: yes
D: but having reduced stamina is obviously something in everyday life, we don’t notice it because we don’t use our maximum capacity so often anyway.

The norm expressed with content words are to a great extent about the expected level of physical achievement of the expected child and how one should address those wishes. The doctor’s argumentation strategy for questioning this norm is to address a series of existing false dichotomies and argue for seeing health instead as a continuum, placing the sick child in it.

In example 1, the doctor introduces the topic, which we might call ‘level of achievement’, the meaning carriers being expressions that relate to physical exercise and a context that the participants may associate with this, i.e. physical testing and military training. In this sequence, the normal of ‘maximal working capacity’ is questioned, and the doctor creates a clear distinction between normal everyday workloads and maximal achievement. In this way, the previously used expressions “lowered capacity” and “lowered stamina” will then be relativized. As a result, the new conceptualization is that a lowered level will no longer be noticed in a normal everyday practice. What at first sounds like a severe diagnosis and a negative message transforms through this generalization into a more trivial problem.

In the argumentation presented by the doctor, new evidence is put forward for whether the child’s expected level of achievement will be lower than what would be associated with a good quality of life. The perspective shifts soon to the maximal level of achievement of an individual. The doctor seems mainly to want to create space to soften the norm of a child having a high physical ability, which is the point of departure for the arguments and can thus be assumed to be the dominant view of normality. The effect of this discursive strategy seems to be a dichotomy of norms, something like a person having either a normal or an abnormal level of physical ability, over to a scale (dimension with several steps up to a maximum level). The conclusion drawn by the pregnant couple can, therefore, be that an individual always has several states of physical work capacity, and this also applies to a person with a disability. Because of this, the disability will not be noticed except in cases where extra physical work is requested.

Furthermore, the doctor also normalizes the norm of a one for all common scale of ability by problematizing the relevance of a maximum level in everyday life. The relativizing may be underscored by the generalization, through the use of the inclusive collective “we”. The conclusion being something like we are all the same in that nobody will know what is our maximal capacity. We can ask if this also means that we never notice if we have a lowered capacity, good fitness or the like. The doctor may here be overgeneralizing and simplifying the importance of lowered capacity, in their ambition to explain things to the couple.

In example 1, the linguistic features employed by the doctor seem to be working together to reinforce the impression of the norm in question. Mainly perhaps due to the cluster of keywords within the same topic, such as “maximal work capacity”, “lowered stamina”, “maximum workload”, “in the military”, etc. Additionally, the use of the pronouns “we” and “you” are marking the inclusion of more actors than only the sick child in the continuum of sickness and healthiness. “in everyday life we don’t notice it” and “when did you reach
your max”. The same effect is achieved by the use of quantifying pronouns: “most children”, which can be also seen as a means of constructing an identity for the future child, creating a group in which most of the members have the same development and can be placed at the same place in the continuum. The doctor’s utterances are also rich in markers of degree of knowledge, for example “exactly”, “of course”, “definitely” which communicates to the parents the level of certainty in relation to the norm that is being constructed and deconstructed. Finally, relativization is achieved by a number of antitheses with the use of contrastive conjunctions, e.g. “but that they have reduced strength … ” and negations, e.g. “we do not notice it”.

A similar strategy to relativize the traditional construction of normality of what is a good life is to play down the drama of what might be considered tough news about a future disability of the expected child. This is done in a context of embellishing the narrative of the child’s future life.

Example 2

(D = doctor, M = mother)

D: when you face challenges that are a bit more tough, then it is the strategy that it’s the same thing; take, for example, one of these climbing walls that are two meters high and you need to jump over it; no I realize that I cannot jump over it I’ll walk around instead

M: mhm

D: and that’s how it is with children, and whichever task they are given, you know no this is too much for me, then I choose to avoid them; they choose other strategies, if for example the others go too fast in maths at school

M: yeah

D: yes, but these ones they have another attitude they might go in the back a bit cooler they don’t need to

M: no

D: be first in the queue, but they instead come strolling with their hands in the pockets.

The doctor narrates in the future child’s voice “I’ll walk around instead” and summarizes the child’s consideration in a concise way, “choose other strategies”. Here are two hypothetical but concrete situations that seem to be relevant to illustrate how a disabled person works, a climbing wall and the school lunch queue. The relativization initiated in the previous example continues here through the introduction of an additional scale dimension beyond the physical dimension. Coolness or ability to solve problems seems to be correlated with the choice of not overdoing things. Here, parents are offered “other strategies”, i.e. cognitive problem-solving and attitude, as alternative ideals in addition to physical performance. In this way, the argument develops with new topoi, everyday situations and alternative strategies. The doctor seems to be questioning the deficit norm of the sick child described in terms of a spoiled identity and paints a picture of a sick but smart child with a strong and cool identity. At the same time, a fallacy of false dilemma occurs in what appears to be a correlation between impaired physical ability and increased cognitive problem-solving ability. Possibly it can be seen as another dominant and widespread norm, about the notion that a disability sharpens other senses. However, heart failure has not been shown to lead to increased problem-solving, rather, on the other hand, heart failure sometimes causes cognitive difficulties.

The arguments are even here reinforced by discursive strategies employed to strengthen the construction or deconstruction of the norm. The doctor is here using a rich narrative with the use of the personal pronoun “I” in order to re-enact the child’s voice and thus construct the additional dimension of coolness: “I realize I cannot jump over, then it I’ll walk around instead”. In this utterance, the doctor is also employing a topos of consequence “I cannot … then I’ll walk around” that adds to the image of a hypothetical child with high cognitive abilities.

In summary, the two examples from a consultation visit show that new understandings are being built up for the parents. They seem to serve as the basis for a renegotiation of normative and unproblematized expectations of the children by parents. The doctor paints vivid images of how life with a heart failure can be. They seem to create a balance between different perspectives in a clear educational ambition to provide a more realistic or nuanced image. At the same time, we can identify doubts in the new perspectives of the expected child’s prognosis. There are overgeneralizations, false dilemmas and incorrect conclusions. Possibly, one must see the educational ambition as superior: the balance between different perspectives besides the traditional view of normality that is hardly questionable without clear options is very relevant. The important thing seems to be that the pregnant woman should understand that there are other ways of being a child than being physically active, sporty and enduring. This can lead to more imaginings about their future children to choose from than merely having a disability. Normalization has an important function here, but at the same time it is difficult. Creating a continuum instead of sharp boundaries between sick and healthy, and a multi-dimensional image rather than unidimensional can create ambiguities which a heart failure can actually lead to in future life.

Parents negotiating norms

In the previous section, it becomes evident that parents are rather passive during the first consultation with the cardiologist. However, they have subsequent meetings all through the pregnancy. After the child is born, they also meet periodically with medical professionals. In this section, we turn our analytical lens to discursive constructions made by parents. We analyze data from interviews, parental blogs and other parenting statements. This data comprises situations when parents compare their child to other children, construct the child as healthy and deprive it of disability, much in the same way as the doctors in the previous section. Medical expert normalization therefore seems to be influencing parental discourses in dealing with their children’s disease. One aspect of normalizing is that parents may need to clarify and legitimize their decisions on how to care for their children. We see it as part of the deliberation that the parents themselves undertake and
conduct. Another aspect is when parents design the child as normal to the environment. Then, the argument seems most relevant to how the child will be perceived, and thus treated, by the environment, for example by other parents and children, teachers, etc. This may cause parents to consider both the risks and gains of a normalization of the child’s condition. What are the consequences of constructing the child as sensitive and vulnerable, or designing it as not so sensitive and vulnerable?

**Re-constructing duality**

We can see several examples of a dual approach to children with heart disease: regarding the child as sick creates tension, but so does regarding it as healthy. There are plenty of examples of resistance to both discourses in the data, and both may have a dominant status in their specific context. Normalization occurs not only in viewing the child as “any other child”, but also in the sense of making sickness a normal case.

Norm resistances are most often expressed through antitheses, for instance in adversative conjunctions such as ‘but’, ‘even though’, etc. They point out that parents have to deal with a duality about how normal the child is/will be. In the following example, the parent describes their child in terms of what a “normal life” means:

**Example 3**

(M = mother)

M: They have said that, after the operation, he will be able to live a normal life, yes he will not be an athlete, but he will be able to have a normal life () just regular controls and then they can … then it feels that it will be an ordinary child then, even if there will be a tough period with operations; you don’t get this first baby time the same way, this is something that you get to miss but it is worth it like so.

The “normal” life is constructed with repeated findings of a usual, ordinary life. In the Swedish original text, the phrase used is *vanligt liv*, which can be translated as common, or ordinary life. This means that the normality construction depends on the double meaning of the word, i.e. something like both normal and frequent. The ordinary life is to the opposite of being an athlete, which is made the reference point to the thoughts. In this dual perspective, the child is compared with healthy children from a sports activity point of view. It is of interest to notice the similarities of this point of view with the argumentation put forward by the doctor in the earlier examples. The construction of a normal life that does not necessarily entail sport activities seems to be contextually filtered in the parents’ discourse of normality.

Antithesis creates a counter-discourse (negations) where the parent positions themselves toward the normal. Content topoi include the two poles that the comparison moves between, a sporty life and a normal life, resulting in a renegotiated view of a (normal) life without sport. The normality construction going on here, i.e. normal children do run and sport, is challenged and face resisted. The concept of normal (usual) is given a broader meaning, although vaguely defined. There is, however, another perspective that applies to the first time with the child, which seems to be summarized in the term “this first beastly time”. That normalization also meets opposition, and is renegotiated as not indispensable (“it’s worth it kind of”). The balance between healthy and unhealthy, or normal and unnormal, is being painstakingly elaborated in this brief example. The parents’ filtering of the situation means that they need to negotiate to a great deal with themselves and their preconceptions, particularly as the norm of healthiness as related to sport is rather dominant.

In the next example, the point of departure is also the dominant conception of sporty children. The argumentation about the body seems precarious, since the description swings even tighter than in the previous example between the two poles of children being generally normal and normality as contingent to being athletic.

**Example 4**

Mimi is a typical girl with a heart condition:

She has energy for everything, but has poor stamina. She cannot, for example, work so hard at school gymnastics as her friends, but instead she has to take it a bit easier, doesn’t play any ball games, she can walk quite far, but not run any long distances, etc. She has instead chosen to do show dancing and it works very well [...] our doctor said when she was a baby that she will not be an elite athlete, and this was maybe not our goal either, so we were and still are quite satisfied with the result.

In this example, the distance between the child and the construction of normality is closer. The parent designs the child in accordance with the norm of sporty children, although a certain negotiation takes place. The resistance is, however, weak, and the argument is led into a false dilemma, i.e. a fallacy of either-or thinking, in this case, the assumption that children are either physically superior or weak. This false dilemma is discoursally constructed with the repeated use of the conjunctions “but” and “instead”, revealing the two poles painted here by the parent. The parent solves the problem of having to consider the child as weak by relativizing disclaimers such as being “quite satisfied” and “maybe not our goal.” By using these mitigations, they indicate that they have a realistic point of departure. Another common topos used in searching for the “right” discourse is a comparison between different perspectives, along with a response to normality with a realistic attitude. They thus adapt to normality by accepting a semi-sporty activity such as show dancing instead of the preferred one of ball games, thereby softening the severity of the norm.

**Negotiating the significance of illness**

A related normalization strategy to comparison with healthy children is by comparing the medical condition to lighter diagnoses. In the following example, it is clear that the parent...
feels that the diagnosis in itself designs the child in a certain way. The child’s condition is somehow viewed as socially constructed in the meeting and dialog with others. This view is also similar to the consultation sessions at the doctor’s office, in which the significance of physical capacity is downplayed and reconstructed as a social norm that needs to be negotiated.

Example 5

But instead we have a child who happens to a bit like when you happen to have a child who has dyslexia or asthma you shouldn’t it is important not to say like that this is Nils and he has a heart condition, you don’t say like this, hi my name is Therese and I have dyslexia, that’s not what we do, but it’s very common that parents, like it is very important not to, that’s what I think at least, give him a diagnosis when he himself doesn’t know that he has it and like make him sick.

Denoting the child as healthy or sick seems to work as a discursive construction, rather than being considered an indisputable handicap for the child. The norm assumed by the parent seems, therefore, to be that medical conditions depend on the way they are addressed in line with how other qualities are constructed. This norm may go back to a widespread discourse of socio-psychological factors governing medical health. The normality construction can be identified as something like “every condition must be pronounced at all times”. An alternative norm is claimed when the parent takes a clear stance against what is expected, namely a traditional view of how disabled children are to be addressed and related to. This argumentation is discursively constructed with a topos of deduction: it is common that parents name the children’s sickness – naming the sickness makes children sick – therefore we should not name the sickness. Another common discursive construction here is the topos of comparisons, comparing heart defect with other conditions in order to balance them: “a bit like”, “you don’t say”.

In comparison with previous examples, it may, however, be relevant to question the parent’s perspective and sense of realism, which may be a case of a false conclusion, and thus a fallacy. The child in fact has a heart condition. To what degree can heart failure be merely a matter of de-normalization? One may ask to what degree the child would appear more helpless if it were to be generally constructed as sick. Both norm perception and discursive strategies point to a quite widespread view of children as normal in a fundamental sense, regardless of their heart function, which are features that may be overlooked and downplayed.

The conclusions made by the parent are embedded in a very clear stance, including argumentation building upon a verbal process expressing mitigation and causality, “happens to”, employed to normalize the condition and reconstruct it as ephemeral. This choice of words is simple, and it elegantly creates a difference in how the child’s sickness, as well as disease generally, can be conceived of – even though it leads to a fallacy in reasoning. This effect is further cemented by a strong and clearly expressed resistance to the norm (“it is important not to … ”).

In the above examples the parents have in common the fact that they strive to make the child fit into normality, which is strong good health, although with different strategies and perspectives. Common to their argumentation is a fallacy of reasoning by means of which they relativize the sickness and thus discursively normalize it. There are however instances of the opposite kind of argumentation, where the parents feel the need to reason for their child’s sickness being real and rather severe. In the next example, the parent turns against the norm that children always feel strong, beginning with the claim “I get rather tired”:

Example 6

Luna is six months old now. Yes, I get rather tired of all the comments about how healthy she looks and of the question “but she is healthy now isn’t she? Eh, no she will never have the same heart capacity as somebody with two functioning ventricles, but for being Luna she is OK, this is usually my answer.

This is a good example of a more realistic approach to assumed conceptions of how healthy a child typically is. The resistance to the traditional way of constructing normality is grounded in medical knowledge, and it is similar to that of the doctors’ resistance analyzed in the previous section. All achievement and all well-being must relate to the individual and different contexts of anticipation. The resistance is clearly expressed and departs from a voicing of a hypothetical dialog constructed as typical. Still the argumentation is grounded in a comparison between what can be expected of a child and the actual child: “never the same heart capacity”, “for being Luna”. Being a parent can be difficult if the child’s sickness cannot be stated and taken into consideration and is instead relativized or hidden and, therefore, the argumentation in this example is interpreted as an act of resistance to normalization.

**Negotiating risk**

This section will present an analysis of forum posts in which parents try to establish what is the best way to take care of a child with heart disease. The discussions include possible consequences of following medical expert advice or of resisting it. Several factors may be at play here. Avoiding risk at all cost will perhaps lead to a sacrifice of personal freedom, while resisting advice could lead to taking a risk that one may come to regret later on.

The discussion thread that is analyzed here involves parents to children with heart disease, who discuss the daily care of their children. The thread starter is a parent who asks what type of daycare is to be preferred for a child with a heart condition. Three replies follow this question. They all take the same direction, which is that the parent could ignore the increased risk of infection caused by attending pre-school. The replies are discursively similar, being a kind of involvement narrative, bringing their own experiences to the discussion and referring to a (neo) liberal discourse of the importance of making individual choices. This discourse differs from medical expert advice, being more general, which leads to a reconstruction of determination in the choices one makes for children, i.e. risks are downplayed, and it is better to follow one’s instinct of what is good, both for the child and
the parent – than trying to protect the child from infection at all costs.

Example 7a

Question: The doctors said that a daytime carer is preferable because of reduced infection risk. My partner, who works in childcare, thinks this is bad. How have you thought about childcare?

Answer 1: Our daughter goes to nursery school, even though she is extremely sensitive to infections. She is almost never sick if you don’t count some colds now and then. I think you should do what feels right for you.

The norm claimed in this response seems to be based on some kind of parental instinct. The argument is anecdotal, that is, it is only based on the advisor’s own child, which is probably quite a typical way of arguing in medical forums, namely the tendency to generalize based on their own experience. This is also a case of rather extreme normalization, since the premise is that their child is “almost never sick”, and the conclusion is that the matter could be downplayed. Seen as a fallacy, it would, therefore, correspond to overgeneralization, a premature conclusion on weak premises. However, it should be remembered that there is hardly any other way to argue for parents, other than exchanging experiences from the existence of their own child. A wider evidence base cannot be used because it is not available. The fallacy is, therefore, incorporated into the context. The conclusion is that the writer who initiated the question in the forum should act without adopting a dominant medical standard, but instead according to their own feeling. A dilemma is relevant, that is the dichotomy between the medical expert counsel and parents’ own preferences.

Example 7b

Answer 2: This thing about nursery school you should decide on your own, because placing the child in a "sheltered environment" is definitely not something good, because they are after all firstly children and then sick.

Even in this response, the parent refers to what the questioner’s own preference is. The argument differs, as this is a dilemma. The argumentation is stronger in this response (“definitely not something good”) compared to the previous one, possibly due to this being the next in line of an ongoing dialog. However, it may be a false conclusion to refer to the fact that all alternatives to preschool are to be viewed as a protected environment and altogether bad. The strategy thus seems to be distancing oneself from the disease.

Example 7c

Answer 3: We have taken Trinity with us everywhere even though the infectious diseases specialist and the doctor in child cardiology didn’t think we should. We don’t want to live isolated because then I feel we would go crazy. This is what we’ve done right from the beginning.

In the third answer, we find the same false dilemma as above, where the alternative to preschool is presented as isolation. This line of argumentation is taken up to another level of intensity than in the previous replies. Consistency thinking is striking, and even stronger in this answer compared to the two previous ones: one goes “crazy”.

In all three responses, there is fierce resistance to the norm emerging from medical expert contexts that one should protect oneself from infections as far as possible. Resistance is evident in the content topos in a similar way in all three arguments: “it is unfortunate”, “it feels right”, “decide on your own stand”, “we don’t want”. Discursively, this topos is constructed by repetition and augmentation. The argument that the parent should make their own decision based on the family’s individual needs is repeated with an increased force in each of the three answers, leaving no doubts as to the degree of certainty in the argument. The resistance is based on parents referring to their own instincts, a kind of freedom thinking and their own well-being. Common to the answers is also that they advocate an option as a parent, where the negative consequences of following the expert councils are to be considered. The determination is in a way reversed. The norm states that children with heart disease are more susceptible to infection than others, which could indicate the negative consequences that a resistance to the norm could give. The argumentation here is in line with a neoliberal discourse of individualism, in which making individual choices and taking one’s own decisions is seen as an unquestionable right each and every person has. This right seems here to extend over and replace expert knowledge, since the parents and the medical experts’ perspectives do not coincide.

The following excerpt provides an example of the opposite determinative direction. Here, the issue is to avoid infection to all costs.

Example 8

We got it in black and white to be careful when we were to take swine flu vaccines, we quickly passed the waiting room at the health center, yet he must have been infected there, and it caused serious consequences for him, of course. So we are very careful.

The parent concludes from their own experience of the child’s infection. Here too, the argumentation is anecdotal, since it assumes that the child was infected at the moment referred to, and that the infection was a sign of specific sensitivity (“which had serious consequences for him”). The potential fallacy is marked with an expression of high certainty (“black and white”, “of course”). The argumentation is further discursively constructed with markers of consequence (“and it caused” “so we are very careful”), which give a dimension of logical thinking and thus add to the expression of certainty.

Discussion

The norms negotiated in both every day and clinical situations are about looking at the children’s heart failure from different
perspectives, either emphasizing the aspect of being healthy or of being sick. Thus, in those cases where the heart defect is rather “mild”, duality reconstructs and is reconstructed. The sick and the healthy become applicable as both, the traditional construction of normality or the alternative norm. In the consultation sessions, the cardiologists often create an alternative norm by normalizing the disease, but only after the illness has been explained. Our examples here show that the “mild” cases of heart failure cause the doctor to argue with fairly strong argumentative means already at the first consultation, by creating measurable images of the child’s future life. The duality here is subject to an upgrade of freshness at the expense of the anomaly that has been diagnosed. The child with a heart defect is compared with a healthy child and, by means of a series of antitheses, emphasis is given to the cognitive and physical skills the child might develop, as opposed to the deficits that come with the illness.

Duality by means of up and down gradients also occurs in everyday situations reported by the parents. Depending on the situation and subject, the child is reconstructed as ill but still normal. In the brief examples from interviews, we see that both the sick and the healthy are presented in a somewhat ambivalent discourse, with many antitheses. Here, the healthiness is not as unquestionable as the health described by the doctor in the consultation sessions. Parents seem to be more ambivalent and commute more between the two poles of the duality. They tend to reset normality by using some of the strategies mentioned by Sanderson et al. (2011), such as focusing on the positive aspects of the illness or trying to ignore it, but at the same time they relate to it and come back to it when it comes to taking decisions influencing the child’s everyday life. Normalization is for many parents achieved by a reappropriation of the illness, but lack of medical expertise leads to uncertainty and causes dilemmas as to the implication of the parents’ decisions on the child’s health and everyday life.

The overall, strong norm to which parents relate and which they construct in their arguments is the stigmatization of disease, as previous research has also claimed (e.g. Lupton & Chapman, 1995; Millen & Walker, 2001). In his work on stigmatization as a social process involved in the recreation of human self, Goffman argues that stigmatization depends on whether illness or disabilities are visible or not to other people and thus be rendered discreditable. Many parents in our study seem to be confronted by exactly this dilemma, considering that heart defect is not an illness visible at first sight. The critical question here is whether the child should live a life constantly identifying with the condition of heart defect or if the illness can be in the background of their lives. If they are honest and open about the child’s condition, they risk stigmatization and the spoiled social identity that comes with it, and if they conceal it, they expose the child to potential harm, both when it comes to its health and its future social identity. The dilemma is extended to the point where a parent wonders if the child needs to know about their condition and automatically be labeled as ill and thus identify with the condition, or whether it is something that does not need to be directly relevant for the child. The dilemma of disclosure is confirmed by other studies of chronically ill people. In the study by Seppola-Edvardsen, Sand Andersen, and Bech Risør (2016), cancer survivors experience ambivalence in terms of how much of their health journey they should disclose to family and friends and part of the reason they give for this dilemma is the need to resume a normal life.

Normalization of the illness could function here as the compromise solution between the two poles of the dilemma. For example, the heart disease is seen in relation to the expectations one can have of a healthy child in relation to leisure activities. Antitheses and comparisons are used as argumentative techniques here in order to show that a middle solution is possible between keeping the illness a secret and being honest and thereby stigmatizing the child. Parents try to emphasize normalization in the disease, while at the same time there is a trace of a critical voice left, the one that compares the child with healthy children. By resisting this stigmatizing norm, the parents introduce a new perspective, that of diversity, where children can be different, and perhaps compensate for any weaknesses with other characteristics. For example, a child with a heart condition will not have the potential of becoming an elite athlete (as healthy children do), but they can do dancing or they can be smart and cool, equally important and desirable traits in a child’s development. We see this argument as a clear sign of a late modern perception of diversity and problematization of past forgiveness of stigmatizing perspectives (Giddens, 1991; Westberg, 2016).

However, there are instances where parents show resistance to stigmatization without a diversity perspective. In these cases, the parents invoke a more individualistic discourse or norm on the individual’s freedom, which they consider also includes parents of children with special needs. In our example, several participants in a forum discussion construct a number of false dilemmas in order to argue that the best way to avoid infection is to shun the risks, or narrow them down, in favor of a preference for a normal life, i.e. a life like any parent. However, there is resistance to such a perspective among parents, but it seems to be about concrete negative experiences of having challenged some risk, in this case, influenza transmission. In cases where an individual parent has not had such negative experiences, they can completely waive responsibility for protecting their child from infection – or, in any case, lower the risk by setting it against the parent’s chosen lifestyle. This individualistic perspective can also be seen as an expression of a late modern view, but here we also choose to see the phenomenon as a discourse meeting, where a post-colonial neoliberal discourse increasingly takes a dominant approach to lifestyle and parenting issues. Even in the so-called risk society (e.g. Beck & Ritter, 1992; Westberg, 2016), discourses of safety can be renegotiated in the meeting with a quest for an individual freedom discourse.

To sum up, we have identified three major constructions of normality in relation to the children with heart defects, and we have shown how the parents as well as the doctors in our study relate to these by reinforcing them or distanciating themselves from them in their argumentation. A clinical implication of this study is that clinicians need to be aware of the fact that the norm of stigmatization is a serious concern in the
discursive construction of illness. It is clear that, despite attempts to counteract it, stigmatization in relation to the deformed body (Goffman, 1963) persists, and a lot of the reasoning in relation to children with heart defects circulates around how to diminish it or avoid it altogether. Resisting the discourse of stigmatization often means putting forward the new discourse of diversity, in which an ill child is constructed as not necessarily in a worst position, but rather in a different situation. Living with a heart defect is synonymous to being different, but not necessarily worse than others. Finally, clinicians should be aware that the norm of responsibility but also of freedom to one’s own life choices seems to have a strong influence on parenting practices and on the way individuals deal with their children’s (and possibly even with their own) illness. These norms re-emerge in different contexts in our data and seem to construct, to a large extent, the way we understand who is ill and who is normal, to what extent, and what the implications are. It could be argued that illness and normality can be turned into relativistic terms, depending on what the implications are. It could be argued that illness and normality can be turned into relativistic terms, depending on the norms established and on the discourses that are being used in order to construct them.

Acknowledgments

The work was funded by the Swedish Research Council. Data were collected in collaboration with the project colleagues Theres Bellander, Anna-Malin Karlsson and Ulla Melander Marttala. We wish to thank the three anonymous doctors who let us in to their consultation room and the pregnant couples and parents who participated in the study.

ORCID

Mats Landqvist http://orcid.org/0000-0003-1538-7095

References


