

CHARGE on

Digital Parenting of a Child with Rare Genetic Syndrome with the Help of Facebook Group

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Abstract

This article relies on auto-ethnography to make sense of the role a closed Facebook group can play in the life of a parent with a child who has rare genetic syndrome, CHARGE. The article will use the concept of affordances as a general framework to make sense of the activities in the Facebook group. For Norman “affordances refer to the potential actions that are possible, but these are easily discoverable only if they are perceivable: Perceived affordances”, thus the Facebook group becomes a sum of imagined possibilities. Previous research has identified the following affordances of social media: *identity, flexibility, structure, narration* and *adaptation*. These five affordances will be used to structure the discussion around the parenting experiences.

Keywords: affordances, social media, auto-ethnography, parenting of a disabled child, online support community

Introduction

The birth of a child with a genetic disorder that brings life-threatening complications is an overwhelming experience. I know, as my youngest son – now 4-years old – came too early, with many diagnoses and with several life-threatening episodes. Having been an avid internet user since mid-90s, turning to online environments was the first and the most obvious choice and I found a few Facebook groups that became “lifelines” and invaluable resources for parenting. This article is an autoethnographic journey that is currently ongoing for me. I have three children and I am writing this account on digital parenting with the help of a Facebook group based on my own personal experiences of parenting a child with complex genetic syndrome causing him to have several severe impairments.

My mother and mother-in-law can share their surprise when coming to greet us home after the birth of our first child in 2005, as we, the new mom and dad, were frantically googling in our bedroom to figure out how to use these eco-friendly nappies with our first-born. They were baffled and a bit insulted that we did not ask them, the generation who had had no access to single-use diapers and had thus mastered the cloth nappies. That was twelve years ago and both my husband and I were avid internet users and saw internet as a first resource to get an answer to our question. Eight years on, when my third child was born and soon diagnosed with rare (one in about 10,000 birth) genetic condition called CHARGE Syndrome, internet was my first resource for knowledge. The website for an American based CHARGE Syndrome foundation¹ became my resource and entry-point to scientific research and personal stories about this genetic syndrome. I used my university library to access medical articles from PubMed collections and my training as a PhD in attempts to master the genre of medical academic writing.

However, this is not the story of my quest for knowledge and mastery of the medical jargon. Nor is it the story of championing for my child against the institutional strongholds of the medical community. These are stories to be written in another time. Current article relies on my expertise as audience researcher and internet-use researcher and looks at the affordances of Facebook in raising a child with multiple disabilities. While basing my story on the personal account of an active internet user, I am fully aware that this is not necessarily the same for all the people, but in the spirit of Ricci (2003: 594) I hope that this autoethnography “allows the reader (and the writer) to experience something new – to feel, to learn, to discover, to co-create”.

Locating the study

There is an increasing number of articles written about lived experiences of disabilities, however, these articles almost never make it to the arena of the media studies. Ellcessor, Hagood and Kirkpatrick (2017) point out that while there is a wealth of discussions around disability and media, neither of these disciplines is adequately able to grapple the complexities of disability and media together. Similarly, as there are many studies on the issues of parenting, parenting an *impaired* child is discussed much less. Being new to the field of disability studies, I hope this article is written in line with what Ellcessor and colleagues (2017) point out to be the three core contributions in the disability studies. Firstly, I subscribe to the idea that the disability is socially constructed. At the same time, I still feel that my child has impairments which pose real struggles beyond the ones that society imposes. Secondly, I identify and discuss the way a Facebook community is challenging the “normate” subject position and thirdly, I base this story and emphasis upon lived experience as epistemological basis for making claims.

I am a member of three CHARGE Syndrome related Facebook groups: CHARGE Syndrome, CHARGE Syndrome (UK) supporting each other and CHARGE Syndrome Skåne. The first of these is linked to the US charity CHARGE Syndrome Foundation, the

second is a UK-focused “sister group”, and the third is a local Swedish group (which I joined after we moved to Sweden and met parents to children with the same syndrome as my son). I will focus on my experiences with the first one: CHARGE Syndrome group as it is the largest (with over 6,000 members by now) and also has most traffic and conversations – normally, between three to ten posts a day, with an abundance of reactions and comments.

What is CHARGE syndrome?

CHARGE Syndrome caused, in two thirds of the cases, by a mutation in the gene CHD7; in other cases, the diagnosis is clinical, based on the fact that the child has multiple anomalies and at least one of the following: Coloboma, Choanal Atresia, typical CHARGE external ears and CHARGE vestibular phenotype (small or absent semicircular canals). Every feature of CHARGE can vary from severe to absent and every feature can thus be related to severe to absent disability in that particular aspect. Colobomas affect the eyes causing mild to severe vision loss. Choanal atresia means blockage of nose passages meaning that babies have no way to breathe effectively (as babies learn to breathe through mouth only in 2-3 months of age). External and internal ear abnormalities mean that these children can have mild to severe hearing loss and very poor sense of balance. Often CHARGE is accompanied with heart defects, other breathing related issues, growth problems and cranial nerve damage causing problems with eating, but also issues with facial appearances. The problems with the input mean also that these kids have often difficulties processing the world in the typical manner and that causes a range of educational and behavioural issues that the kids and their parents struggle with. With this list of potential complications, the discussions in the Facebook group also range across a huge variety of topics.

Therapeutic affordances

I decided to frame my autoethnographic enquiry with the concept of affordance, originally coined by Gibson (1979) who refers to the potential of action that can be taken with material objects or technologies. Norman (2013: 145) adds: “affordances refer to the potential actions that are possible, but these are easily discoverable only if they are perceivable: Perceived affordances”, thus the Facebook group becomes a sum of imagined possibilities. I will explore the affordances of the Facebook group through the lens of the affordance as “best anchored, not as latent capability innate to the technology, but as a potentiality that only exists when leveraged within a specific domain and set of actions” (Majchrzak et al., 2013: 39). Thus the affordances outlined hereafter are based on my experiences and observations in the CHARGE Facebook group and are less universal properties on social media technologies or even Facebook.

However, to connect to the larger discussions of affordances of social media in medical situations, I am using Merolli and colleagues (2013) who have utilized the concept of affordances to do a meta-analysis of medical studies looking at chronic disease management. They identify identity, flexibility, structure, narration, adaptation to be the five key affordances of social media and in a later work (Merolli et al., 2015) operationalize this list for survey research and label the same five as “therapeutic affordances”. I find these affordances helpful as, while children with the CHARGE Syndrome do often not qualify as chronically ill, the processual nature seemingly never-ending struggle has many similar features.

The global-local dimension of Facebook group

Before embarking on a more detailed discussion of the affordances, the geographic nature of the group needs to be briefly discussed. The Facebook support group is in English, so while there seem to be people who use the group also with the help of machine translation features, the majority of the discussions are in English. That sets up a barrier of being an active member, as it requires mastery of written English. The group is also attached to US-based charity. This means that while global in reach, the discussions end up being still often American: dominated by the US and to a lesser extent Canadian participants. Other English-speaking countries as the UK, Australia and others can also be seen as more active in comparison to smaller countries with other languages. There are overwhelmingly more mothers in the group, although sometime fathers, grandparents, siblings or medical specialists also join the discussions. There are also a few young adults having CHARGE Syndrome who contribute to the discussions with their personal reflections or seeking advice in relation to dating, jobs, internships etc. The group has a few academics and doctors who are experts on different aspects of CHARGE syndrome and who are connected to the charity who are regularly called upon to give expert-advice.

Identity affordance

Identity: Preferences regarding identity disclosure (Merolli et al., 2013; 2015). While Merolli thinks it is important to be able to choose the level of disclosure in regards to identity construction, I see a different kind of identity-related affordance. With Facebook being increasingly personalised and detached from the notions of anonymity, the parents in the Facebook group mostly use their real names and at least proximate locations to help to connect with other people. Thus the affordance is not related to anonymity. However, Merolli and colleagues (2013; 2015) also operationalise this through the preference to control the amounts and sorts of things other people know about a person and I can more readily relate to that idea. Closed Facebook group still means that your private

Facebook profile is protected unless you become friends with someone and then more information is shared to that friend. Otherwise, the people will be with their real names (most likely) connected through the online identities they construct.

As the concepts of healthy and sick are changing with the advances of medical science and with general democratization and opening the society, a larger diversity can be accepted. Traditionally, it is the healthy majority that has been able to define what is considered “normal” and “acceptable” in society (Foucault, 1990). Today, more and more online venues are discussing intimate and private aspects of individual’s lives in attempts to advocate for changing existing norms and opening the society for accepting a wider range of acceptable practices (Baym, 2015). Parents of the disabled children are using the Facebook group to create an enclave of acceptance and normalisation of their disabled children. While Merolli and colleagues (2013; 2015) can be seen clustering this together with the affordance of narration – recording, sharing and learning from other people’s experiences, then for me, this is also strongly related to identity building. I see this Facebook group as building an identity as the parents through the narratives (which I will discuss below), but also an enclave of normalisation of our different children, which is visible through sharing pictures and videos of their children in four distinctly different categories.

First – children in “normal” activities. This mode would include school pictures, first day in kindergarten, but also Christmas, Thanksgiving, Halloween and other celebration pictures. The pictures are mostly static and demonstrate important occasions often specific to US culture. For instance, the flood of kids in Halloween costumes or fourth of July celebrations can be noted. Birthday pictures are what probably many mothers share on Facebook anyway, but birthday pictures in the CHARGE group have extra meaning, related to the idea of survival. The survival rate of the children with CHARGE Syndrome is 70 per cent to 5 years of age (Blake, 2001) and that means that any of these birthdays are worthy to celebrate. The community also recognises this and shows support with likes and comments.

Second – children achieving milestones. CHARGE Syndrome is in the majority of cases causing numerous developmental delays – sometimes children catch up with the milestones of their healthy peers, other times, some of these milestones will forever remain unreachable. For instance, as children have missing, underdeveloped or different balance organs, sitting, standing, walking, running or dancing are generally harder to master. Thus, part of normalisation process includes sharing these milestones with the Facebook group.

Third – children in hospital/medical situations. The images of children lying on hospital beds, tangled with cords and wires and surrounded by medical equipment are the hardest ones for me. They are also part of the normalisation process. This Facebook group is the community who understands the struggles and the jargon and sees the children underneath the wires. These pictures are emotionally difficult as they remind actively the time when my child was also tangled up in these wires, and these memories are still difficult to digest even if our last hospitalisation was now three years ago.

Fourth – picture for attention/cuteness is a new phenomenon related to people seeking to connect to, but needing to trick the Facebook algorithms. As the technology seems to prefer posts with pictures, people often post unrelated images (mostly still of their child) to their queries. The practice also has a backwards result meaning that they will get more attention and more reactions to their posts, but also more comments in the line of – “I have no answers or can’t comment on the query, but your baby/child is adorable”.² As a combination, the picture for attention affordance is related to identity as the images are also used to reaffirm parents of the cuteness factor of their children, but the original purpose behind the images is the need to trick the Facebook algorithm.

Sharing images and videos is a very important technical feature of Facebook to which the identity affordance relies on. I remember a video from my early time in the group where a 5-year old girl was filmed coming down the stairs without holding on to the handrail. The caption could have been something along the lines – “Who needs these balance organs anyway!”. The feeling of pride, relief and hope that this video gave me has left a deep imprint. I don’t remember who the girl was. But I do remember the feeling of irrational hope that one day my baby will be able to do the same. The hope is irrational as the CHARGE Syndrome is a spectrum disorder, meaning that while some people do really well, others might die early due to complications arising from the syndrome. That makes identification process on Facebook complicated as you feel that this could be my baby with both the incredible success stories as well as the early death that is reflected on the site. You identify yourself emotionally with the mothers who mourn their babies as well as with the ones who celebrate their success.

Overall, the identity as the affordance has been a very important one for me. As a mother, I feel that I can share my kid with the community who understands how special his achievements are. With one of the few posts I have made to the community, I shared the image of my baby writing an alphabet. So far the only time he has done this, but for a kid who had just turned four and unexpectedly decided to show us that all the endless hours on Youtube had paid off by him memorising the whole alphabet and being able to write this, the moment was too precious not to share. For me, the image was a bragging moment, but I hope that it was also a moment of hope and pride to many others who could see that nothing is impossible.

Flexibility affordance

Flexibility affordance is operationalized through being able to choose between synchronous and asynchronous communication (as well as geographic freedom) (Merolli et al., 2013, 2015). The Facebook group for CHARGE parents joins a lot of people across the globe and sometimes people who do not have English as their mother tongue write and seek support from the group. There are some instances where the Facebook group members recognize and utilize flexibility – you can pose your questions and wait for the answers despite the confinements of the time. Being a global group, there are often

active members despite the time, and there are several occasions where mothers post urgent questions (and received replies) also outside doctor's office hours. Sometimes the group is called to help to decide best ways forward. However, there are also examples where questions posted from "wrong" time zones go unnoticed and remain without answers.

The US focus of the global group means that often the discussions are very much US specific. Even if there is geographic freedom, the dominant membership coming from the US also influences the relevance of the topics, and non-US questions are not treated so thoroughly. The specific medical insurance policies, the struggles with particular school systems, success or struggles with particular hospitals are often discussed with a very clear country-specific vocabulary and approach. For me, these discussions have felt less relevant and less applicable. Similar lack of flexibility can also be seen in the discussions of the UK based CHARGE group where the hospital or school system discussions are focused on UK based solutions. Thus, while flexibility is an important affordance, the geographic spread makes some types of posts less relevant to people like me.

Structure affordance

Operationalized in Merolli and colleagues (2015) survey as filtering and guidance as well as the preferred presence of health professional and preferred presence of a moderator, the structure affordance is related towards guiding the patient through the maze of information. In the CHARGE Facebook group, there are group owners, one of whom is an outreach community manager for the CHARGE Syndrome Foundation, but their presence is not visible. The discussions are overall hardly moderated, and the access to the common resources is not always very clear or transparent. However, there are a few expert members as mentioned before and occasionally members use Facebook tag function to invite the person to join the conversation. However, most of the times, people seem to be happy to rely on the collective knowledge of the group rather than expect the experts to have the answer. This reliance is perhaps related to CHARGE being a spectrum disorder – what might work or be applicable on one end of the spectrum might not be applicable in some other instances.

The Facebook group also relies little on the documents and knowledge resource provided by the foundation. In the earlier days of my journey, I also remember people linking to the function of the document of the group, but this seems to be forgotten. Overall, what the Facebook group lacks in regards to the organization and structuring of the information, participants sometimes compensate with linking, tagging and re-posting. I personally find the structure affordance be the least present through the technical aspects of Facebook, but very much there when it comes to the people participating in the discussions. The possibility to ask repeated questions and to be able to rely on not only the new answers but sometimes also digging up older materials is overall very helpful.

Narration affordance

In Merolli and colleagues (2013; 2015), the narration is operationalised through recording experiences, sharing experiences and learning from other people's experiences. For me, this is also related to identity building as the narratives are also used to build the identity as the parent of the disabled kid. When in their survey Merolli and colleagues (2015) find that recording and sharing experiences to be less prominent, then in Facebook, the group heavily relies on that. I do believe that people use posts to vent about the frustrating experiences, to show off the milestones, but often also just to connect. Again, a lot of images are used for the range of these functions and the discussion above about the different Facebook images can easily be seen as doubling or the affordances function. I think that this is different for parents of disabled children compared to adults' disease management. The recording experiences are not that well afforded by the Facebook group once posted, I have had difficulties in going back to the posts to gather my own reflections. It is more of celebrating or despairing about the moment. At the same time, these narrations are my way of connecting to other people as I have shared over the distance the growing up stories of a few children who were babies around the same time as mine. Different stories have given space for some painful comparisons, as even then, other children seem to be better in many issues. But at the same time, this has also motivated me to post my few posts or join in discussions as I have hoped to flag my presence to the group. Lu and Hampton (2017) confirm in a nation-wide survey that social media offers informal social support in the form of companionship, emotional support and tangible aid. They conclude that "the association between frequent status updates on Facebook and perceived social support might in part be attributed to what we describe as 'awareness of other's awareness'" (Lu & Hampton, 2017: 876) and I really want other parents to be aware that I am cheering on to their struggles to the best of my abilities.

Overall, I feel like a lurker most of the times. I think I am not active, but at the same time, if I start counting the occasions I have commented on someone's posts, they are not that few. Weirdly, I think the US centeredness of the group makes me feel that I am more on the periphery and I am holding back in sharing my experiences, as they seem to be less relevant to the overall group. I have not posted start of the school or Halloween costume pictures as school start is still a few years away from my child and Halloween is not that important part of my experiences. I do not fret about needing to normalize my child through shared Halloween experience. However, I find it ingenious how people use the Facebook group as a resource to think of solutions that would help to normalize their children and their experiences. A lot of children with CHARGE cannot eat orally, however particularly Halloween in the US is all about candy and sweets. I am fascinated by how important it is to the parents to think of solutions where their non-eater kids would have as much joy from the festivities. They have thought, and shared signals in their community where differently coloured door decorations can be used to mark the houses where Halloween treats other than candy are shared. I do hope

that power of social media is enough in these instances to share the good vibes and positive experiences to all children and that the physical impairments are not leaving the children socially disabled.

Adaptation affordance

Adaptation affordance is related to the adaptability of social media to suit the frequency and type of use (Merolli et al., 2013; 2015). Elsewhere in the literature, people have established the idea that the difficulties with medical information management include the fact that not always do people need similar information at any given time (e.g. Lubi, 2017). The information needs and behavior change based on the needs of the particular moment. Facebook groups can in this sense keep up and be adaptive to individual's needs. With complex medical needs needing to be prioritized at different moments, the attention and focus of the Facebook page also have varied for me. I have found myself hungrily reading almost every post that I have found in the group at the earlier stages of diagnosis and learning to cope with the situation. At other times, feeding and food-related topics have been very important, and I have read and also commented to many feeding related posts as I sensed I had accumulated knowledge worth of sharing with other community members.

For Merolli and colleagues (2015), the affordance of adaptation relates to the attention given to social media in related to stable or flared stage on pain. Similarly, parents to children with CHARGE syndrome have different stages where they need a different type of advice and support. The first year and the subsequent years until age five tend to be most dangerous, but also most overwhelming. There are parents often asking: "Will this ever become easier?" and always multiple reassurances follow confirming that there will be this sense of coming out of the woods. The Facebook group brings together people who have done CHARGE parenting for more than twenty years with the ones who have just received their diagnosis. The sharing of the experiences through narrations supports the adaptation possibility. I remember being hungry for the experiences which would indicate that things can and will be ok, but I am always heartbroken for the losses of these kids shared on Facebook. While the loss of a child keeps the danger looming much closer than it would be otherwise, my son is four, soon five and thus out of the most dangerous times. At the same time, the positive experiences shared by other parents help me immensely.

Conclusions and limitations

This experience has not discussed the ethical, privacy-related issues, the critical dimension of parents giving medical advice to each other. Rather, the discussion has been rather positive and uncritical as this is based on my experiences. While writing this

article, I have reflected on the feeling of being in the fringes of the community, but at the same time, wanting to share with others in the same situation that they are seen, they are heard, and when possible, they are supported.

Notes

1. <https://www.chargesyndrome.org/>
2. These and other quotes are imaginary and are results of generalisation, not actual quotes from any person posting in the Facebook group.

References

- Baym, N. K. (2015). *Personal Connections in the Digital Age*. Cambridge, Malden, MA: John Wiley & Sons.
- Blake, K. (2001). Life Expectancy in CHARGE <https://www.chargesyndrome.org/wp-content/uploads/2016/05/Life-Expectancy.pdf>
- Ellcessor, E., Hagood, M. & Kirkpartick, B. (2017). Introduction: Toward a Disability Media Studies in E. Ellcessor & B. Kirkpatrick (eds.), *Disability Media Studies* (pp. 1-30). New York: NYU Press.
- Foucault, M. (1990). *The History of Sexuality: An introduction*, Vol I. Trans. Robert Hurley. New York: Vintage.
- Gibson, J. J. (1979). *The Ecological Approach to Visual Perception*. Boston: Houghton Mifflin.
- Lu, W. & Hampton, K. N. (2017). Beyond the Power of Networks: Differentiating Network Structure from Social Media Affordances for Perceived Social Support. *New Media & Society*, 19(6), 861-879.
- Lubi, K. (2017). *The Role of Information Search and Interpretation in Living with Chronic Illness. The Case of Estonian Parkinson's Disease Patients*. Tartu: Tartu University Press.
- Majchrzak, A., Faraj, S., Kane, G. C. & Azad, B. (2013). The Contradictory Influence of Social Media Affordances on Online Communal Knowledge Sharing. *Journal of Computer-Mediated Communication*, 19(1), 38-55.
- Merolli, M., Gray, K. & Martin-Sanchez, F. (2013). Health Outcomes and Related Effects of using Social Media in Chronic Disease Management: A Literature Review and Analysis of Affordances. *Journal of Biomedical Informatics*, 46(6), 957-969.
- Merolli, M., Gray, K., Martin-Sanchez, F. & Lopez-Campos, G. (2015). Patient-Reported Outcomes and Therapeutic Affordances of Social Media: Findings from a Global Online Survey of People with Chronic Pain. *Journal of Medical Internet Research*, 17(1). <https://doi.org/10.2196/jmir.3915>
- Norman, D. (2013). *The Design of Everyday Things: Revised and Expanded Edition*. New York: Basic Books (AZ).
- Ricci, R. J. (2003). Autoethnographic Verse: Nickys Boy: A Life in Two Worlds. *The Qualitative Report*, 8(4), 591-596.