

WEBSITES BLOGS: AN ANALYSIS OF PARENTING A CHILD WITH SPECIAL NEEDS CHALLENGES

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ABSTRACT: *Blogs are online published materials or journals where different community members can express, communicate, and share their news and experiences through posting photos, videos, and audios. This article investigates website blogs that were authored by parents of children with special needs (SN), from the last five years (2014 - 2019) and analyzes the challenges parents encounter which are related to social life experiences and the way they feel when facing these challenges. The collected data were processed with the WebQDA software and analyzed by Content Analysis. We could see that all parents, regardless of their kids' special needs, face challenges related to accessibility, child's characteristics, people's reactions, and child with SN behaviors, and experience a lot of positive and negative feelings when they're dealing with these challenges.*

KEYWORDS: website blogs, parenting, special needs, social life challenges

INTRODUCTION

Parenting a child with SN challenges

Parents play a crucial role in promoting their children's behavioral, social, and emotional development because they spend most of their time with them. Therefore, poor parenting skills can impact a child's development and well-being. Parent's circumstances including poverty, single or young parents, parental depression, lack of education, and unemployment are risk factors for having a child with developmental problems. In general, most parents face various challenges in parenting their children as a result of changing their lifestyle, for instance; increasing childhood obesity, and sleeping problems (Hutchings, Owen, & Williams, 2018).

Parents of children with SN can encounter many psychological and health issues as a result of raising their children with disabilities. For instance, parents of children with ADHD, hearing impairment, Autism Spectrum Disorder (ASD), epilepsy experience a high level of

stress, depression, and anxiety due to their children's behavioral, communication problems, academic performance, and mental issues. Parenting psychological and health issues found to be associated with the type and severity of the problem, child's age and lack of social support (Muñoz-Silva, Lago-Urbano, Sanchez-Garcia, & Carroll, 2017; Park & Yoon, 2018; Singh, Lancioni, Winton, Karazsia, Myers, Latham, & Singh, 2014). Particularly, looking after a child with severe or multi-disabilities can cause not only psychological issues but also physical problems, e.g., headache, back issues which impact their health and well-being (Arim, Miller, Kohen, Guèvremont, Lach, & Brehaut, 2019; Yagmurlu, Yavuz, & Sen, 2015).

Additionally, financial difficulties as a result of unemployment, low income, or struggle to have a full-time job are contributing in many physical and mental health issues and impact parents' wellbeing (Feeg et al., 2018; Jackson, Liang, Frydenberg, Higgins, & Murphy, 2016; Smith & Grzywacz, 2014; Yagmurlu et al., 2015). However, empowering parents by providing them with training programs can enhance their ability to cope with their child problems (Jackson et al., 2016; Smith & Grzywacz, 2014; Yagmurlu et al., 2015). Overall, financial and social status, child features, social support are risk factors that impact both children with SN and their parents' health and well-being (Arim et al., 2019).

Parenting a child with SN can impact parents' social life as a result of the nature of the disability. For instance, some parents avoid participating in social activities because of the embarrassment of their child's behavioral issues, e.g., seizures, particularly when it happens during their participation in social occasions with family or friends (Ozanne, Verdinelli, Olsson, H. Graneheim, & Malmgren, 2016). Furthermore, parents' busy schedule impact their ability to participate in social events. For example, some parents find difficulties to manage daily life activities, e.g., schoolwork, mealtimes (Koch, 2016).

Lack of information and social support can be challenging for most parents of children with SN. For instance, a lack of knowledge to cope with the child's behavioral problems can lead parents to use inappropriate parenting styles to control the child's behaviors, e.g., using punishment which consequently impacts the child's academic and social success (Muñoz-Silva et al., 2017). Similarly, lack of knowledge about children with SN nutrition can drive parents to use inappropriate feeding habits which consequently contribute to psychological and physical health issues, e.g., fatness or anorexia (Polfuss, Simpson, Neff Greenley, Zhang, & Sawin, 2017). Moreover, lack of social support from schools and community can potentially increase parents' mental health issues, e.g., sleeping disorders, and fears (Ozanne et al., 2018). Besides, the lack of communication among families of children with SN might deprive them of sharing their daily life experiences (Wo, Ong, Low, & Lai, 2018).

Many studies showed that parents who were provided with coping strategies training programs were more capable of addressing their children with SN difficulties and having a low level of stress (Koch, 2016). Moreover, parents' involvement in their child's intervention program can decrease the level of anxiety and be more satisfied with their children's social behaviors. However, parents with bad experiences could discourage other parents from seeking intervention (Shepherd, Landon, Goedeke, Ty, & Csako, 2018).

Parenting and website blogs

Since the appearance of the "World Wide Web" in the twentieth century and the availability of accessing devices (smartphones - computers), parents started accessing the websites and social media for seeking information or sharing their experiences about parenting. Through these websites, parents discuss various topics about parenthood, e.g., pregnancy, and daily challenges. Indeed, some websites are general, and others are specific for a category of parents, e.g., parents of children with SN, or single mothers. These sites allow parents to speak freely without any obstacles compared to in-person interaction, which can be difficult for some parents. Therefore, parenting websites can benefit parents by promoting their self-esteem and decrease the emotional and mental issues, e.g. stress, and depression (Lupton, Pedersen, & Thomas, 2016).

Mothers of children with SN have been using blogs to express and share their feelings. Besides, mothers find blogs as a platform to express their life experiences in raising their children with SN without any barriers and share things that may not share with relatives or close friends. Moreover, blogs help parents with a similar situation to share their daily life experiences. However, blogs are not only a platform for parents but also assist people with SN to express themselves and communicate with others through the internet, particularly, for children and adolescents with ASD who have social communication difficulties. As a result, blogs contribute to increasing the level of health and well-being of people with special needs and their parents (Yelena, 2016).

However, the content of blogs about motherhood was criticized and described as insignificant and without value. As a result, many mothers posted blogs about their life experience by stating that "it is not mommy-blog" to avoid the stigma of "mommy - blogger." Additionally, there was criticism about using mothering blogs for commercial purposes from famous mother's bloggers who promote companies' products targeting mothers (Crosby, 2011). However, there is a suggestion that mothers should share the details of their experience if the content is beneficial and related to motherhood (Yonker, 2012).

Investigative questions and objectives

According to the literature review, parents of children with special needs face many challenges in their family life and blogs are a way of expressing their concerns, problems and share experiences. Therefore, to know the challenges that parents of children with SN face on their social life and the feelings involved within these experiences, the research questions and the specific objectives that guide this study arise:

1. What are the aspects related to special needs that influence family social life and entertainment times?

To analyze what the parents mentioned as major challenges when they were going out or traveling with their children with SN.

2. How do the factors emerging from the first question, affect parents of children with SN?

To characterize the feelings of parents when experiencing social activities with their children with SN.

METHODOLOGY

According to the objective of this investigation we chose to carry out a qualitative descriptive and interpretive study as a circular (not linear) methodology that requires creativity and flexibility of the researcher and the use of diversified instruments to interpret the phenomena in terms of what they mean for the subjects (Coutinho, 2018; Denzin & Lincoln, 2005).

The blogs in question were examined with WebQDA software (Costa, Moreira, & Souza, 2019) and analyzed by the content analysis method.

Data collection and analysis

We selected the data for the present study by choosing blogs from a website that gathers the top 30 Disabled & Special Needs Child Parenting Blogs. The website ranked the blogs based on the following criteria:

- Google reputation and Google search ranking
- Influence and popularity on Facebook, Twitter, and other social media sites
- Quality and consistency of posts.
- Feedspot's editorial team and expert review

Within all the blogs included in the website, and to reduce the sample, we selected the blogs which were written by the mother, the father or both parents of children with SN in the last five years (2014-2019). Based on these criteria, we excluded the blogs started before 2014; those were written by parents of adults with SN and the blogs which gathered stories of different families.

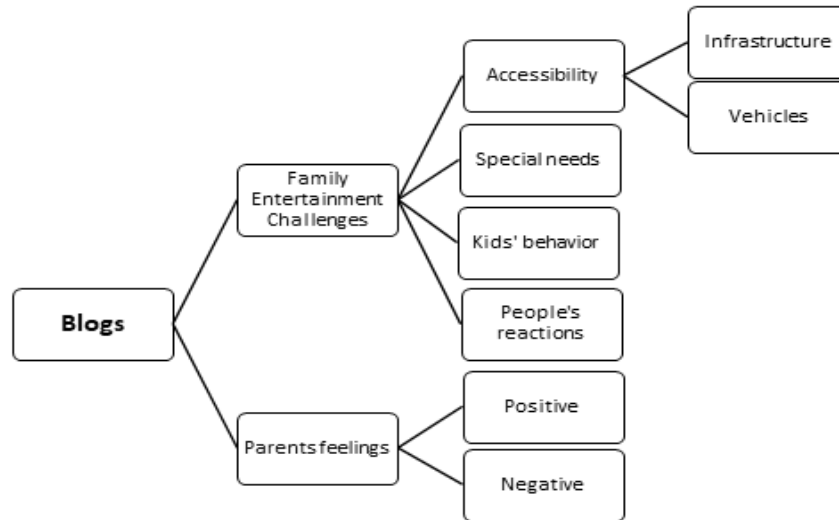
According to the inclusion and exclusion criteria mentioned above, in the end, we selected six blogs as follows:

Blog 1 (B1) *Unbreakable Sara* <https://unbreakablesara.com/>; **Blog 2** (B2) *See the Seitz* <https://seetheseitzfam.com/blog/>; **Blog 3** (B3) *Not The Former Things* <https://nottheformerthings.com/>; **Blog 4** (B4) *Life with a side of the unexpected* <https://lifewithasideoftheunexpected.com/>; **Blog 5** (B5) *Atypical Familia* <http://atypicalfamilia.com/> and **Blog 6** (B6) *My kid loves broccoli* <https://mykidlovesbroccoli.wordpress.com/>

The data were treated with WebQDA software (www.webqda.com), to support the analysis of qualitative data in a collaborative and distributed environment developed by researchers at the University of Aveiro. According to the objective of this research, the corpus consisted of excerpts (units of analysis) about the challenges parents of children with special needs experience related to social life and the feelings involved in this experience.

RESULTS AND DISCUSSION

We follow the content analysis techniques according to Bardin (2011): pre-analysis, data exploration and treatment of the results (inference and interpretation) to classify the units of analysis into two dimensions, each of them corresponding to a research question and specific objective: i) Family Entertainment Challenges; ii) Parents Feelings. The categories and subcategories for content analysis emerged from the text inductively and are classified as shown in Figure 1.

Figure1. Representation of categories and subcategories for content analysis

According to what parents expressed in the selected blogs about their main concerns and feelings during entertainment moments with their kids with SN, we analyze two dimensions: Family Entertainment Challenges which is divided into four categories: a) Accessibility which includes two subcategories: (i) infrastructure and (ii) vehicles; b) Special needs; c) Kids' behavior; and d) People's reactions. And the dimension of Parents Feelings, which is divided into two subcategories: (i) positive feelings and (ii) negative feelings.

The definitions of the categories are presented below for a better understanding of the encountered concepts and ideas.

Accessibility is the ability of people with SN to access the environment “infrastructure, vehicles, and devices, etc.” despite any obstacles.

Special Needs are special requirements and treatments that a person with a disability requires.

Kids' Behavior is the kind of action that kids with special needs show as a result of the nature of the disability.

People's reactions are the behaviors that people show as a reaction at kids with SN characteristics or behaviors.

In order to have an overview of the data obtained from each blog, we show a table that relates the sources, dimensions and categories and the number of references we identified in each of them.

Table1. References according to sources, dimensions, categories, and subcategories

Family entertainment challenges					Feelings involved		
Sources	Accessibility		Special needs	People's behaviors	Special kids' reactions	Positive feelings	Negative feelings
	Infrastructure	Vehicles					
B1	0	2	1	1	0	3	7
B2	4	1	8	4	1	18	13
B3	1	0	12	6	8	6	7
B4	1	0	8	1	0	6	10
B5	1	1	4	4	8	4	0
B6	0	0	2	2	5	0	2
Total number of references	7	4	35	18	22	37	39

DISCUSSION

Family entertainments challenges

Accessibility

In five out of six blogs mothers mentioned about accessible vehicles or infrastructure difficulties, when they were talking about their experience in traveling with their children with SN or when they were spending social occasions with their family and friends. For instance, the mother in B1 described the difficulties to get her daughter in and out of the car or wheelchair. Similarly, the mother in B2 talked about accessible infrastructure difficulties when she was taking her daughter to the pool.

"Riley isn't going to get any smaller, and it's already pretty difficult to get her in and out of our current cars. Also, the new wheelchair isn't exactly the lightest. We may not need it right this minute, but it will be needed soon". B1

"The pools were zero-entry so her chair could just roll right in if needed!" B2

"As special needs parents, we work hard to make accommodations and put the necessary modifications in place so our kids can succeed in different environments." B4

Some mothers of children with SN complained about the lack of accessible infrastructure and vehicles; however, there are also many positive comments related to this topic. So, data shows that accessibility is an issue that concerns most families of a child with SN, despite there are specific entertainment places where the efforts to minimize these problems are evident, especially in the United States, where the blogs writers are from.

"Everything is made for kids, especially those with physical disabilities." B2

"She told me that before a single announcement was made, the gate agent would come and personally escort us to the gate for essentially pre-boarding." B3

"Or maybe it's because JetBlue supports the autism community and strives to make flying easier for special needs families." B5

Special Needs

This seems to be a fundamental issue for parents of children with SN since all the six blogs pointed out some challenges related to their child's disability or characteristics more than once as we can see in Table 1. When comparing the number of references to each item, we can see that Special Needs is the second mentioned reference with 35 references, which shows that this is a big concern for parents when they are going out or traveling with their children with SN.

While mothers in B1 and B2 mentioned their children's physical needs, e.g., feeding, changing the diaper, and bath chair, the mother in B3 wrote about the needs of her son with ASD to board before loud announcements because of his sensory issues. Similarly, the mothers in B4 and B5 referred to their children with ASD sensory needs. Furthermore, the mother in B6 expressed the need of looking after her paralyzed daughter to avoid emergencies.

"Our little angel is currently still in a crib". B1

“To make matters even more pressing, she had a diaper that needed changing [...] we carried extras of everything (including the G-tube) [...] we also had a bath chair, extra Special Tomato stroller and Oxygen waiting for us in our room”. B2

“Take my son with his with massive sensory issues and rigid thinking. Now add holiday travel, sleeping in unfamiliar places, the noise of a large family all crowded into one space, new foods, no routine, the anxiety of wanting to open presents, the anxiety of all of the presents now being opened, the sheer exhaustion of not sleeping well, and not eating well”. B3

“Consider your child’s sensory needs only participate in holiday activities that will not overwhelm your child’s sensory system”. B4

“Norrin has a tough time when I go out to throw away the garbage, can’t imagine myself traveling to another country without him”. B5

“We grappled with small and rather spirited small, but a heavy, child; freeing her from her special buggy and carefully placing her on a grown-up bench – daddy positioning himself so that if/when she spontaneously and violently threw herself backward, she would be safe and no little heads would be cracked open and subsequent emergency medical attention required whilst on holiday”. B6

As we can see, special needs cause parents to be anxious when they go out of their home, which is related to children's physical and mental needs or their medical care or feelings.

Kid’s Behavior

In the 4th subcategory, mothers mentioned about their special kid’s behaviors as a challenging factor. For instance, mother in B3, B5 and B6 reported their kid’s way of acting regarding the surrounding environment, e.g., kicking, crying, self-harming, anxiety, screaming, and fears which put parents in bad situations to control their child’s behavior and resulting in more parental stress and anxiety.

“He kicked the chair and refused to sit down [...] He took one of his gifts and smashed it into pieces [...] My son began wildly flailing, crying, trying to find anything to break or to hurt. He scratched his arms and his face. He scratched my arms and my face”. B3

“Before we left our apartment, I began to sense Norrin’s anxiety [...] Norrin refused to sit down. And when he did sit down, he refused to buckle his seat belt. He began screaming, “Stop! Let me go!” and “I’m afraid! Tears were streaming down his cheeks, his face was

red and he was breathing hard. He was clutching at the seat in front of him. I could see the fear in his eyes". B5

"Granted, Hannah did eschew her fork and chose to eat with her hands; whilst occasionally rubbing her lunch into her eyes/ears/face/hair/clothes/the table/us/a passing dog/anything else...but hey, she was feeding herself and she was happy, so that was all that mattered, really". B6

Even though parents try to prepare their kids with SN to face different environments and people before going out or traveling, they can't predict or prevent how the kids will behave, as they are not able to control the entire situation. So, we can see this is an issue that causes parents' concern and anxiety.

People's Reactions

People's behaviors regarding a child's disability can be challenging for most parents. For instance, the mother in the B3 mentioned about the reaction of her family regarding her son with ASD behavior. Similarly, the mother in B2 described the accident that her daughter had when an older lady drove her scooter straight into her daughter's wheelchair.

"She quickly said, "you don't qualify" and walked away leaving me literally speechless." B1

"My family stared at me and the message was clear. Are you going to let him behave like that?" B3

"The only mishap we had that first day was while waiting in line, an elderly lady on a Rascal scooter rammed into Hudsyn's wheelchair and nearly clipped her arm". B2

Besides the real challenges they face, they are always worried about the way uneducated people respond to their children's disability, as we can see in the following excerpt:

"No doubt there'll be times when other people, uneducated people, narrow-minded people with little tolerance for or understanding of difference react less favorably." B6

Data shows that other people thinking or reaction could be a hard challenge for most parents of children with SN when it comes to social life and entertainment.

Parents' feelings

In the selected blogs mothers expressed about their positive and negative emotions which have experienced with their child with SN during family entertainment times. For instance,

the mother in the B1 talked about her frustrating time of waiting for her government to provide her daughter with the health insurance, as well as, the mother in B2 expressed about her fears and concerns in traveling with her paralyzed daughter. Furthermore, in B3, the mother of a child with ASD talked about her embarrassment feelings regarding her child's behaviors when they spent their Thanksgiving with her family. Similarly, the mother in B5 expressed her fears and concerns traveling with her child with ASD. Finally, the mother in the B6 talked about her stressful and anxious times while she was traveling with her paralyzed daughter.

"I'm upset too that I have a job, I have insurance, I'm doing everything right and I can't get approved for services [...] I know there are a bazillion other reasons to be frustrated with the government, but this one hurts your family directly". B1

"What if she pooped on the plane - where would we change her? What if she got really sick - where would we take her for medical care? What if her G-tube came out and we didn't have an extra one with us". B2

"The Thanksgiving and Christmas I just described, were the last ones we celebrated before learning that my son is on the autism spectrum. To me, they are a blur of stress, sadness, anger, and fear". B3

"We felt helpless and completely exposed. Joseph was frustrated; I was on the verge of tears. it was one of those rare moments when we just didn't know what to do". B5

"...all I wanted right there and then wasn't the ground to swallow me up". B6

In contrast, mothers in the selected blogs expressed their positive feelings that they have experienced with their child with SN in family entertainment times. For instance, in B1, the mother expressed her happiness regarding the strength of her paralyzed daughter. Similarly, the mothers in B2 and B6 described their overwhelmed and relief feelings when they traveled with their paralyzed daughter. Moreover, mothers of children with ASD in B3, B4, and B5 expressed their joyful and happy feelings when traveling or celebrating Thanksgiving with their families. Most of the blogs talk about feeling relief as a positive feeling, which shows parents of kids with SN are always expecting an embarrassing situation, and when it doesn't happen, they feel relieved.

"Riley is amazing. She's strong, and I don't know what I would do without her strengthening me every day". B1

“You’ll see me getting emotional on the train ride. Y’all, I rarely cry. But, the amount of overwhelm...the relief...I had after finally getting to this incredible place and learning it really IS everything they described it to be, I couldn’t help myself”. B2

“I was in relieved, grateful tears”. B3

“We were all somewhat relieved for the slower pace, respite from electronics and time spent together. It was what our souls needed”. B4

“I’m happy I took a chance because our trip to Universal Orlando was not only an amazing experience it was filled with a few life lessons”. B5

“Phew! (all that preparatory work did pay off in the end). that was a relief”. B6

The mothers’ negative feelings expressed, such as frustration, anxiety, stress, sadness, anger, fear, and shame. In contrast, the positive ones, e.g., relief, happiness, admiration, proud, show that being a parent of a kid with SN is like a rollercoaster of emotions because it is a condition full of challenges.

CONCLUSION

Website blogs have been used by many parents of children with SN to describe their experience about the challenges they encounter in family entertainment times. In the selected blogs, parents expressed about the challenges they have experienced in traveling or spending time with their family on social occasions. We observe that the challenges they faced are related to accessible infrastructure and vehicles; although accessibility is becoming more extended, there are many places in which they still have difficulties. Other challenges mentioned are related to their child’s characteristics and behavior regarding the sensitivity to the surrounding environment, which they relate to the reactions of uneducated people towards their children and environmental stimuli. In all these experiences, the parents are constantly going through a mix of positive and negative feelings when they are spending family entertainment activities with their children with SN.

Recommendation

We recommend making another analysis of website blogs that were written by people with special needs themselves, to examine which kind of challenges they experienced to understand their point of view regarding everyday life challenges and eliminate these challenges.

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