

Digital storytellers: Parents facing with children's autism in an Italian web forum

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Abstract

The diagnosis of Autism Spectrum Disorders (ASDs) in children has a relevant impact also on their parents. Parental websites offer opportunities to share social support, personal experiences, and health-related information. This study aimed at exploring how parents of ASDs children use specific online forums for ASDs. We selected an online forum of parents of ASDs children and analyzed 2469 messages using the latent thematic analysis. We identified four major themes, that we defined in terms of: The supporting group; the difficulties; the activities; and a perspective know-how. Results showed that parents with ASDs children often experience a need of emotional and practical support to cope with the difficulties with their lives. The online community seems to allow them to share experiences and solve doubts about their parental role, proposing practical advice and sustaining them. Belonging to the same group further acts as a support for parental well-being through peer similarity.

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Keywords:

Autism; Parenting; Internet forum, E-group; Thematic analysis.

DOI: 10.6092/2282-1619/2019.7.2104

1. Introduction

The American Psychological Association (2019) has defined autism as the most severe developmental disability with onset in the first three years of life. Autism Spectrum Disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). Thus, its diagnosis could represent a critical event in the family life.

Literature has demonstrated that parents of children with ASDs report a higher level of stress and increased depressive symptoms associated with the challenges of caring their children, when compared to parents of children with other disabilities or typical development (Hartley, Seltzer,

Head, & Abbeduto, 2012; Hayes & Watson, 2013; Navot, Jorgenson, Vander Stoep, Toth, & Webb, 2016; Weiss, Wingsiong, & Lunsky, 2013). Furthermore, the ASDs diagnosis often reduces the levels of parental satisfactions (Howlin & Moore, 1997; Samadi, Abdollahi-Boghrabadi, & McConkey, 2018) and indirectly affects parental behavior (Totsika et al., 2013; Weiss et al., 2013). Moreover, despite a very recent study found that shared experiences of raising a child with autism brought parents closer (Sim, Cordier, Vaz, & Falkmer, 2019), the ASDs diagnosis seems to negatively impact on the couple's relationship (Molteni & Maggiolini, 2015; Papp & Hartley, 2019) and the well-being of the entire family (Navot et al., 2016). Considering that the problems related to the ASDs diagnosis can significantly reduce parental well-being, the implementation of effective support or intervention strategies seems necessary (Jones et al., 2018; Pennefather, Hieneman, Raulston, & Caraway, 2018; Sim et al., 2019; Webb, Jones, Kelly, & Dawson, 2014). According to Fleischmann (2005), the child's condition causes impairment of parental functioning, so parents have to find and employ specific strategies to manage individual and family routines in light of the child's behaviors (Gentles, Nicholas, Jack, McKibbin, & Szatmari, 2019; Ooi, Ong, Jacob, & Khan, 2016; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Waizbard-Bartov, Yehonatan-Schori, & Golan, 2018). As Vassallo (2016) highlighted, parents of children with ASDs often display intense 'child-centered' states of mind, so that they may desperately and continuously search a way to help their child. Sometimes, this becomes a parental life's work, and parents frequently set aside their own needs, dismiss their usual activities, reframe their vocations, so that their quality of life can be compromised.

For these reasons, parents of children with autism may need increased services and social support. The request of more social support implies a variety of activities, such as the expression of positive affect between people, social reinforcement, and the provision of guidance or information (Nieuwboer, Fukkink, & Hermanns, 2013; Plantin & Daneback, 2009; Scharer, 2005; Suárez, Rodríguez, & Rodrigo, 2016b). This might help them to cope with stressing situations and depressive feelings (Fleischmann, 2005; Ooi et al., 2016).

Today, the Internet offer a great opportunity to create online groups and to take part in social media communities, which can provide individuals with positive social support (Boursier, Manna, Gioia, Coppola, & Venosa, 2018; Niela-Vilén, Axelin, Salanterä, & Melender, 2014).

A number of studies describe the many benefits of the participation in online support groups, such as emotional and instrumental support, community connections and protection, and anonymity which allows the individuals to express themselves with a relative sense of safety

(Brady & Guerin, 2010; Drentea & Moren-Cross, 2005; Dworkin, Connell, & Doty, 2013; Hall & Irvine, 2009; Jang, Dworkin, & Connell, 2012; Palmén, Korpela, & Saranto, 2012; Pedersen & Lupton, 2018; Ruthven, Buchanan, & Jardine, 2018; Suárez, Rodrigo, & Muneton, 2016a), despite it reduces socio-demographic information availability about the users (Holtz et al., 2012).

Drentea and Moren-Cross (2005) especially highlighted three main categories of communication through the internet parenting websites: (a) *Emotional support*, which includes the possibility to vent stress and frustration; (b) formal and informal *instrumental support*, which allows parents to share personal and professional practical information; (c) *community building/protection*, by which the members recognize violators of the community norms and protect and reinforce their own sense of participation to the community life.

Online communities contributed to parents making a transition from being passive consumers of information of their children disorders to becoming active searchers and producers of information (Alsem et al., 2017; Boursier et al., 2018; Brazy, Anderson, Becker, & Becker, 2001; Plantin & Daneback, 2009). In fact, the web seems to allow parents to create online communities based on shared interests (Kirk & Milnes, 2016), activating groups composed of different individuals who share similar problems but offer different perspectives, experiences, opinions, and sources of information (Brady & Guerin, 2010; Suárez et al., 2016a). Also, these communities allow parents to receive Internet-based peer support, despite the geographical distances or time constraints (Niela-Vilén et al., 2014). In this respect, the online peer support groups had become an endless source of medical data and social assistance (Plantin & Daneback, 2009).

Therefore, three main aspects emerge from this brief overview of the literature: Internet has become a useful tool for parents to seek and obtain information (Alsem et al., 2017; Boursier et al., 2018; Brady & Guerin, 2010; Jang et al., 2012; McDaniel, Coyne, & Holmes, 2012; Plantin & Daneback, 2009; Reichow et al., 2012; Walker et al., 2017); direct or indirect participation in the conversation in the online groups, sometimes fostered by anonymity (Jordan, 2010; Qian & Scott, 2007; Suler, 2004), may reduce inhibitions (Kraut et al., 2004) and may facilitate the parents to be honest about their own opinions and feelings (O'Connor & Madge, 2001); this participation to online groups fosters feelings of acceptance and social support (Baker, Sanders, & Morawska, 2017; Holtz, Smock, & Reyes-Gastelum, 2015; Niela-Vilén et al., 2014).

Of course, online forums and groups cannot constitute an alternative to high-quality professional websites (Reichow et al., 2012) because of the risk of inaccurate information (Jordan, 2010), but these communities are a rich source of comparison, practical advice, and

medical information. However, since parents represent a large category of e-health users, it remains important for the care of children that online services with accurate information are available, particularly if they focus on mental health issues for parents of children with special needs, such as ASDs (Alsem et al., 2017; Nieuwboer et al., 2013).

An Italian study on families of patients with rare diseases (Tozzi et al., 2013) showed that the 66% of parents participate in online forums on health. Ninety-nine percent of these parents searched for information on disease characteristics, 93% on therapy, 89% on diagnosis, 63% on alternative therapies, and 62% on nutrition, demonstrating that Italian parents of children with rare diseases are active Internet users who search for information and join online communities. Additionally, several studies highlighted that peer-support groups provide particular benefits for parents of children with special health-care needs, such as sharing social identity and learning practical information (Shilling et al., 2013), increasing knowledge and skills, advocacy and support (Alsem et al., 2017; Kingsnorth, Gall, Beayni, & Rigby, 2011), and reducing feelings of isolation and stress (Moqbel & Little, 2014). Notably, peer-support groups represent an important source of support that cannot be replaced by supplement professional support (Niela-Vilén et al., 2014).

Peer-support groups have a key role for parents of children with ASDs, because of their stronger desire for support and information caused by their children's special needs (Ooi et al., 2016). Supportive Internet forums offer the opportunity to share experiences about parenting (Kirk & Milnes, 2016) and to stop social isolation experienced by some parents, helping them to cope with the symptoms of ASDs (Jordan, 2010).

The interest in Internet use by ASDs parents is increasing. Fleischmann (2005) conducted reviews of narratives posted online by parents of children with autism and Asperger syndrome, and Mackintosh, Myres, and Goin-Kochel (2005) used web-based questionnaires to identify what sources mothers and fathers use for information and support. This latter study demonstrated how other parents of children with ASDs are often the first source of information and support, more than any professional group. Reichow et al. (2012) conducted a study on autism-related websites, distinguishing between high-quality ones with a top-level domain of *.edu* or *.gov* and poor-quality websites that promote non-evidence-based practices. Successively, several researchers carried out studies to evaluate the quality of information in a sample of autism-relevant websites (Grant, Rodger, & Hoffmann, 2015; Hall, Culler, & Frank-Webb, 2016). Moreover, also the scholar interest in parental motivations behind the internet use is increasing.

Indeed, the need of parents with ASDs children to search information and emotional support has been emphasized by several recent studies (Abel, Machin, & Brownlow, 2019; Alsem et al., 2017; Reinke & Solheim, 2015). Such studies analyzed mainly online support groups for this category of parents (Clifford & Minnes, 2013), examined parental posts on Facebook using a deductive content analysis (Roffeei, Abdullah, & Basar, 2015), and used semi-structured interviews with parents using the interpretative framework of phenomenological analysis (Ilias, Liaw, Cornish, Park, & Golden, 2016; Reinke & Solheim, 2015).

In the light of the aforementioned studies, the current research aimed at exploring how parents of children with ASDs use specific online forums dedicated to ASDs.

2. Method

2.1 Participants

One hundred usernames attributable to the personal profiles of 24 fathers and 76 mothers of a child with ASDs have been identified in a forum for parents of children with ASDs. The gender and the geographical origin of forum users were explicitly declared on parents' personal forum profile, whereas no father or mother had declared age.

2.2 Procedure

After approval of the study by university IRB for psychological research, data for this study were collected on the Internet by searching for Italian websites including forums on Autism Spectrum Disorders. Forums were searched on Google search engine using the correspondent Italian words for the terms "autism", "forum", "parents", "children". One forum specifically directed to the caregivers of children with ASDs, with parents coming from all over Italy, and it was selected because of users' frequent daily activity and the variety of themes discussed. We extracted 42 relevant forum threads that have been written in a time frame of three years (2015-2018).

After a first summary reading of posts and personal users' account, threads were selected using following criteria:

1. Written by a caregiver of an ASDs child;
2. Written or active from January 1, 2015, to November 30, 2018;
3. 10 or more replies.

We collected 2427 comments in the original 42 threads. Each thread with comments was copied into a document for applying latent thematic analysis, yielding to 2469 total posts to be analyzed. To preserve forum members' real identity (Kraut et al., 2004), all the identifying data in the text were omitted, such as the Internet forum name, names or pseudonyms of the writers, or references to places. Also, the usernames or URLs for any specific threads were omitted. Therefore, it is not possible to identify any single forum user in our final results.

2.3 Data analysis

According to the guidelines described by Braun and Clarke (2006), a Latent Thematic Analysis was realized to identify, analyze, and report themes from a qualitative source of data. An inductive data-driven analysis was conducted through an analytic process, which moves from the data description to the interpretation. Indeed, the thematic analysis entails research across the data set to find repeated patterns of meaning, mainly in the latent thematic analysis the development of the themes themselves involves an interpretative work. Precisely, a thematic analysis at a latent level "goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualizations" (Braun & Clarke, 2006, p. 13).

As Braun and Clarke (2006) highlighted, the Latent Thematic Analysis is not a linear process from one phase to the subsequent one. Rather, it is a recursive process and consists of different phases, where the researchers move back and forth as needed, throughout them (Table 1). First, two of us independently and simultaneously read all the material to familiarize with the data corpus, and after a "repeated reading" of the data in an active way, searching for meanings, patterns and so on, they wrote notes on the margins to select interesting contents. The codes could refer to semantic or latent contents that appear interesting to the analysts. Gradually, from these contents, they created a preliminary list of codes, writing notes in the text, using highlight colors to indicate potential patterns or to identify segments of data. Later, we started to analyze the codes matching them up with data excerpts, considering how different codes may combine to form an overarching theme, and thinking about the relationship between codes, themes, and different levels of themes. Following Braun and Clarke (2006), we discussed the findings, and a critical revision of proposed themes was conducted to guarantee internal homogeneity and external heterogeneity (data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes). Finally, main themes emerging from latent thematic analysis were plotted by means of a thematic map of the analysis. In this way, it was possible to make sense of patterns of meaning (Braun & Clarke, 2013).

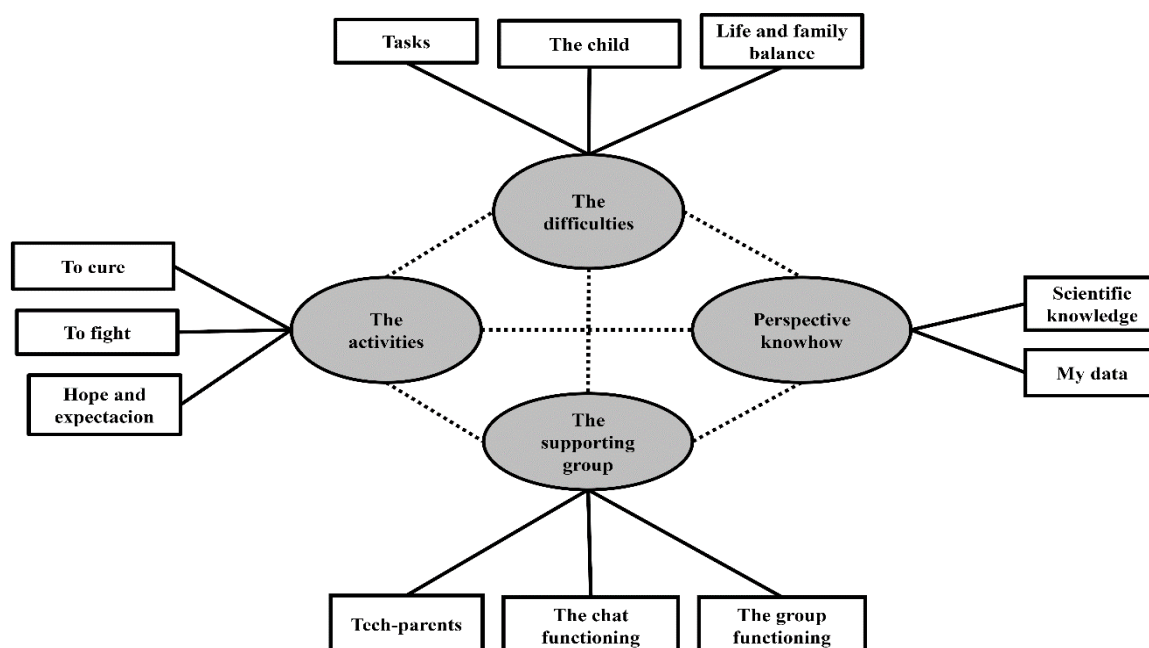
Table 1. Phases of thematic analysis (adapted by Braun & Clarke, 2006)

Phase	Description of the process
1. Familiarising with data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis (eventually including a thematic map).

3. Results

Four main themes emerged from our thematic analysis, resulting from the final identification of 45 codes and 11 subthemes. The four main themes were: The supporting group; the difficulties; the activities; and a perspective know-how. These four themes and their connections describe the complexity of the relations among parents, children, and autism. Moreover, they all seem to translate how parents make sense of their difficult experiences finding online emotional and informational support (Figure 1).

Figure 1. The map of themes connected to the categories.



The themes were so called: *The Supporting Group* (42.65%); *The Difficulties* (32.83%); *The Perspective Know-How* (13.55%); *The Activities* (10.97%). On the total frequency of the codes, it has been calculated the percentage of the sub-themes and, consequently, the percentage of the themes. Even though Latent Thematic Analysis is not based on advanced statistical analysis and invites researchers to consider the emotional value that can be captured beyond the data description (Braun & Clarke, 2006), this amount should be considered as it refers to “the weight” the online group dynamics and functioning have in this context. The first two themes are the more frequent ones, and they mainly concern the online group dynamics, and the dimension of the “Autism spectrum” difficulties. The other two themes proper relate to the parents' activities (Table 2).

Table 2. Codes frequency of the 2469 messages.

THEMES (% on Total Sub Themes)	SUB-THEMES (% on Total Frequency)	CODES (Frequency)
THE SUPPORTING GROUP (42.65)	Tech-parents (2.56)	Backlink (202) Online\offline (67) Self-promotion (51)
	The chat functioning (9.92)	Emotional outburst (178) Playfulness (563) Provocation (193) Reassurance (268) Censorship (40)
	The group functioning (30.17)	Practical advice (628) Personal opinions (1069) Curiosity (448) Decision making (245) Emotional sharing (850) Gratitude (215) Digital storytelling (129) Us versus the others (190)
THE DIFFICULTIES (32.83)	Tasks (5.01)	Breathless (122) Step by step (242) Perseverance (156) Immediacy (85) Wistfulness (23)
	The child (10.17)	The real child (823) The child and his peers (48) The disappointing child (402)
	Life and family balance (17.65)	Parent as researcher and therapist (542) The deprived parent (110) Side by side (341) Economic issues (131) Daily planner (246) Self-questioning (59) Worries (173) Unconfident/confused (371) Which “us”? (235)

PERSPECTIVE KNOW-HOW (13.55)	My data (6.16)	My legal knowledge (166) My medical knowledge (604)
	Scientific knowledge (7.39)	Handbook (66) Specialists (859)
THE ACTIVITIES (10.97)	To cure (5.71)	As an ideal parent (144) The body and behaviors (443) Testing and proving therapies (128)
	To fight (1.62)	Personal guilt (58) Autism as a parasite (145)
	Hope and expectation (3.64)	The ideal child (164) Goals (219) Dissatisfaction (72)

3.1 The Supporting Group

Three sub-themes and 16 codes characterize this first main theme. It refers to how parents share their personal experiences and knowledge with people interested in the same argument, and how mothers and fathers improve their technology-related capabilities, offering their help and suggestions to the group memberships through practical advice. Online relations sometimes also lead to an offline meeting and an occasion to build a close friendship (*Online/offline*).

"Hi, everybody! Finally, I found a forum made especially for us, parents of special babies!" (Mother)

"As you may have noticed, on this web-portal you can find lots of information... In this forum, there are so many documents, stories, questions, sharing, mutual aid, and solidarity. So, welcome among us!" (Mother)

The online conversations allow parents to prove their own knowledge and to narrate experiences, which sometimes are easier transmitted by Internet links or enriched by photos and video records (*Backlink*).

"Among the many articles I translated, I recommend you this one... It's my favorite! [link]" (Mother)

"Despite intestinal discomforts... My son is a hero (and his mom too!) [video]" (Father)

Similarly, to a typical face-to-face group, this e-group has a *chat functioning* based on both *provocation* (i.e. conflicts and arguments) and *playfulness* moments (i.e. jokes and complicity), reinforcing cohesion and intimacy among members. For example:

"That's not true! Don't be silly, please! The endoscopy is generally prescribed AFTER, as and when necessary" (Mother) [Nitpick]

"I couldn't miss your baby's birthday... Happy birthdayyyyyy by all of us!" (Mother) [Playful]

Sometimes the webmaster (the leader and the forum founder) manage the members' conversations and implement rules in all chat rooms, rarely assuming the role of *censorship* to control who has too discordant opinions.

More generally, chat rooms become the places in which *emotional outbursts* (releases of negative and strong emotions) are permitted, accepted and held back by *reassurances*.

"It worked for us... Anyway, bugs for you... At first, it's hard, but you'll find you have strength and intelligence you need!" (Mother)

"We're all in this together! You won't miss support and advice by this wonderful group! We're here, you're not alone" (Father)

Furthermore, the *group* performs several *functions*. It allows the comparison of different experiences reported by parents who share *practical advice*, or simply offer *personal opinions*. Thus, the online group holds and process parent's negative feelings, giving new and more acceptable points of view:

"Great! When I'll have results, I'll compare them with yours!" (Father)

Moreover, ASDs parents seem genuinely interested in each other (*Curiosity*) and able to identify themselves with other parents' feelings (*Emotional sharing*).

"I read your story and I know how you must feel! I feel like you and perhaps it helps you to feel less alone... My heart goes out to you, I'm going through this too and I think you're an amazing father. Wits and courage!" (Mother)

Older users of the forum often become a reference point for the new members and their opinions are esteemed to help grateful parents (*Gratitude*) to improve their *decision-making* process, as a source of practical advice and examples to follow. Frequently mothers and fathers narrate their own experiences and these digital stories become a sort of diary in which they note their children's improvements and complications (*Digital storytelling*).

"After several days of absence, I'm back with an update..." (Mother)

"I reread some updates of months ago and now my son's having less sleep problem, but nutrition... Not close to good enough!" (Father)

Thus, the key elements of the online group seem to be, on the one hand, the research of something to share, through a *comparison* with the peers (parents with similar experience) and, on the other hand, a 'struggle' against other parents who do not have children with ASD. The comparison with someone who feels your own feelings and offers a personal opinion without judgments can improve parents' self-esteem and create a sense of closeness despite the virtual meetings or the geographical distances because all the members belong to the same group. They constitute an *"us against the others"*.

"For decades they insist on the "refrigerator mother" matter... there will be always some "experts" with their self-referential pearls of wisdom" (Mother)

"They make me so bad!!!I'm disgusted..." (Mother)

3.2 The Difficulties

Three sub-themes and 17 codes characterize this second main theme, which mainly refers to the everyday life practical and emotional difficulties of parents with children suffering from an ASD.

"Sometimes, I realize how the autism hit not only my son but, in a way, all of us. After few months friends don't call you anymore, no one comes to visit you. So, after the first 'flare', when there are a lot of 'if you need, call me!', the fire dies and you sunk into oblivion" (Father)

The autism spectrum influences and entirely occupies parents' and children's time and life. Thus, often they seem to become one entity with the autism and this overwhelming mixture imposes several *tasks* and *breathless* running, characterized by urgency, orderliness, and *perseverance*.

"Might sound a little cruel, but these children are severely diseased. The autism is a pervasive disorder. If you don't intervene NOW it will undermine the entire life of your baby" (Mother)

"The path of our children is a marathon, not a race. It takes dedication and perseverance" (Father)

Despite the *wistfulness*, helped and sustained by other forum users, parents are pushed to immediately (*Immediacy*) and promptly intervene on their children's treatment and persist, *step by step*, even if the achievements are slow in coming, through progress and worsening.

"I'm speaking as a "veteran" and I'm telling you it is!!! It is two steps forward and one step back. It's a long road!! This is a marathon. Be patient and don't give up!" (Mother)

The autism spectrum disorder puts the parents in front of the difficult and limited reality. The spectrum is the *real child* with his effective skills, capabilities, and needs. The parents lose their ideal baby, the child they likely dreamed during the pregnancy and the first months, to find a new and sometimes *'disappointing' child*, often unable to relate to *his peers*.

"When he was 14 months old he started kindergarten... There was a clear difference between him and his peers" (Mother)

Through their interactions, parents seem to verbalize their anxiety and doubts about themselves and the ASDs (*Self-questioning*, *Unconfident/confused*), and the *worries* they undergo about their experiences with their children, transmitting it to the other members of the group, in the hope that they can help to cope with these feelings. Parental messages express mothers' and fathers' pain for their child's condition:

"In this moment I'm so shaken! Over a few hours my son voluntarily bit his head three times... He has never done anything like that... He didn't bit it so strong to get hurt, but believe me, in this moment I'm in a lot of pain..." (Father)

Deprived of their ideal baby, the ASDs parents here narrate their sadness and discomfort, their loneliness and the discovery of a new way to be a couple in a fight (*Side by side*).

"I suppose you should understand the mood of a parent who would like to play with his son, but the child ignored him because he's enraptured by faucets and little doors" (Father).

"I spent wonderful years: The cohabitation, the wedding, the first son and my daughter arrived on the first try. Everything seemed fine and always I said: 'I would like to take a picture of this moment to make sure it will stay that way... It's perfect!'. I thought that life was kind with me and I felt lucky. Unfortunately, first suspects arrived: That word 'autism' whispered by my wife convinced me to click on an Internet link that pushed me to face life's hard reality. I cried so much, I was mad, and I lost 10 kilos in few weeks and it was so hard to wake up in the morning. I thought: 'If my life will be like that... Maybe all this isn't worth it!'. But now, I and my wife are learning to be a team in which every member is ready to help the other who is in troubles. Obviously, there are moments of struggling but they are stages of a match and we want to win this badly!!!" (Father)

After the diagnosis, the family and parents' life are completely transformed, and mothers and fathers have to improve the *life and family balance*. The children's difficulties involve the redefinition of life activities and personal identities in parents. ASDs parents have to face a new parenthood with its challenges, reorganizing their *daily planner*, their working time, the family routine (*Which us?*), and the family budget (*Economic issues*). Parents need to conciliate their job responsibilities with the care their children with ASDs require, sometimes sacrificing their personal identity to become a sort of *therapists and researchers* for their own needs of knowledge, sometimes splitting themselves between their parenting and supporting duties:

"Parents should learn to stay in parenthood boundaries and they shouldn't become pedantic therapists to not lose their own baby" (Father)

"As the doctor told us: 'The child recovery almost exclusively depends on parents. Few hours of psychomotricity, speech therapy, and ABA are not enough. You parents have to take matters into your own hands!'. This sentence influenced our next choices. Shortly we became our son therapists and coordinators of other therapists' activities." (Mother)

3.3 Perspective Know-How

Two sub-themes and 4 codes characterize this third main theme. Both the parenting challenge and the desire to be a good enough parent encourage mother and father to work hard, improving their capabilities as a caregiver.

"Where did you learn all this? I would like to do the same!" (Mother)

The parents refer to two sources of information on *legal* and specific *medical* issues: materials they personally collected in their experiences and scientific data. Indeed, parents of children with ASDs appear focused on increase their knowledge about autism, learning as much as possible about treatments, best practice, legal policy, and bureaucracy.

"Come on, go to 'biomedical program' and 'ABA' sections of the menu and start!" (Mother)

Scientific knowledge sometimes serves to solve parenting doubts and to fulfill a desire to understand. By reading *handbooks* or referring to *specialists* suggested by the other members, mothers and fathers can build a "personal portfolio" (*my knowledge*) they can share with the other worried parents and proudly show them.

"Look through the documents we posted. You should read, research, and study by yourself, because many things won't be explained to you" (Mother)

Through articles and information made available on the forum, the senior users offer a list of specific books, handbooks, and specialists to which the new members can refer and turn to.

"In 'Helpful contacts' section you can find information about two doctors: More or less they are the only ones" (Father)

This knowledge reflects the perspective know-how the parents need to follow and share with peers.

3.4 The Activities

Three sub-themes and 8 codes characterize this fourth main theme, which seems to essentially refer to the "active" parental condition.

"...having the head engaged in "doing" rather than in "thinking" (Father)

Mothers and fathers, sometimes *as ideal parents*, sometimes as parents who feel ashamed of their child's condition, need to be constantly busy, to feel themselves doing something. It seems that

"actively doing something to your child is one of the biggest incentives to continue" (Father).

Furthermore, these parents work very hard to try to *cure* their children's bodies, mind, and behaviors, sometimes with a specific diet lacking gluten and casein, food supplements, psychomotricity, speech therapy, and ABA, fighting against the *autism as a parasite* and "*facing the battle against the monster*" (Mother).

But the parents have to fight also with their *guilt*:

"Instead, now I'm realizing that in my ignorance I did not understand what was really happening to my child" (Father).

"At the moment I'm mad at of myself to not listening to my instincts" (Mother)

The parents of this forum would *test the therapies* and *prove* that they set the right course and the success of achieved *goals* confirm this point:

"But you have already given us good news! How many achievements in no time! Less food selectivity, imitation, symbolic play, cognitive goals... How many beautiful things I've read! Don't give up and you will see how many achievements you will get even" (Mother)

They feel to get closer and closer to *the ideal child* they wish and reading about others' experience sustains their own confidence.

"It's going well, I think! Not bad socialization, he reads, writes and plays basket with peers and without support, what else would I want? He also prepares food with educators!" (Mothers)

"How many beautiful things I read ... I'm happy and I hope that with the beginning of kindergarten he will begin to relate to other children, to learn from and with them. It is a difficult path, but we can do it!" (Mother)

Indeed, despite achieved goals, often parental expectations are *dissatisfied*, therefore, there is a great deal of work still to do. Parents feel to be on the right course, but sometimes it seems to be getting longer.

"I'm following with great interest your path and I hope to do the same with my little one. When I removed gluten from his diet my little man seemed possessed, but then suddenly, as if by miracle, he started to do things that seemed very distant. Of course, it is not enough but reinforces hope" (Mother)

4. Discussion

The supporting group, the difficulties, a perspective know-how, and the activities emerged as the emotional core themes of the parents of children with ASDs in the analysis of the forum's posts. The findings of this study confirm that caring for a child with ASDs represents an additional and long-term challenge (Hartley et al., 2012; Molteni & Maggiolini, 2015; Navot et al., 2016; Ooi et al., 2016; Weiss et al., 2013) and that e-groups may have a key role for the caregivers (Alsem et al., 2017; Boursier et al., 2018; Jordan, 2010; Kirk & Milnes, 2016; Moqbel & Little, 2014; Shilling et al., 2013; Suárez et al., 2016a).

A recent study highlighted how parents of children with ASDs experienced multiple challenges in different aspects of care (i.e. negative emotional response to diagnosis, difficult child, reorganization of marital and family daily life, etc.) (Ooi et al., 2016). According to these

previous findings, in this study the ASDs diagnosis seem to force parents to accept their real child with his or her peculiar difficulties. Therefore, negative feelings such as disappointment, frustration, uncertainty, confusion, guilt, and anger may be connected to the autism condition, and it could be difficult for parents, though necessary, to reorganize life projects and family plans. In this regard, autism is a long-term challenge: the child's diagnosis may be perceived as an overwhelming event, too complex and unpredictable to understand. As “digital storytellers” the posts analyzed in the autism’s forum show how difficult it can be for parents to face a diagnosis of autism in children, which may absorb and overwhelm their lives, sometimes involving them in an exhausting struggle. Furthermore, it seems to enlarge how narratives could contribute to improve individual's meaning-making and resilience in case of chronic diseases, as well as parents' sensemaking of children's clinical conditions (Freda, Savarese, Dolce & De Luca Picione, 2019; Martino et al., 2019; Parrello & Giacco, 2014). Many of these parents try to improve the quality of life of their children and their family, so they persistently and diligently follow this purpose, even in Internet forums, to the point that sometimes it seems that there is no break for the parents of children with ASDs: Many of the parents in the forum, in fact, seem to be constantly engaged in a battle. Treatments, therapies, exercises, handbooks, and medical consultations rapidly become their work as parents, researchers, and therapists. The parental capabilities to face the new situations will improve according to the children achievements in a step by step process. To organize, plan, and control seem to be the best solution to deal with difficulties and feelings of powerlessness. According to previous studies, “doing all you can” and “never give up” terms seem perfectly describe the ASDs parents’ perseverance (Hall & Graff, 2010; Ooi et al., 2016; Woodgate, Ateah, & Secco, 2008).

Literature shows the importance of social networks and Internet forums to sustain people in difficult stages of life and experiences (Alsem et al., 2017; Brady & Guerin, 2010; Kirk & Milnes, 2016; Martino, Gargiulo, Lemmo, & Margherita, 2019; McDaniel et al., 2012; Niela-Vilén et al., 2014) and parental need for information and social support - particularly for parents of children with special needs (Alsem et al., 2017; Baum, 2004; Dabrowska & Pisula, 2010; Fleischmann, 2005; Jones & Lewis, 2001; Lam & Mackenzie, 2002; Nieuwboer et al., 2013; Plantin & Daneback, 2009; Scharer, 2005; Skotko, 2005; Suárez et al., 2016b; Webb et al., 2014). In this respect, participating in a forum group may guarantee an emotional and concrete support, in a potential space that is virtual but may have important real and potentially positive effects. The use of online forum seems to help parents to acquire knowledge, to share information and experiences about the characteristics of their child’s disorder, the most appropriate therapies, the management of everyday difficulties. Online forums may also allow these parents to share emotional support among them and to stop isolation (Jordan, 2010; Moqbel & Little, 2014).

By telling their stories, the parents may share their doubts and anxieties, and by receiving support from the others they may feel reassured and may find the energy to continue their “battle” against the ASD. This is a peer-support function of the forum that clearly emerged in our study, and that seem to have almost only positive effects in the parents’ life. According to Reinke and Solheim (2015), the need to be connected and understood is an ongoing part of the life in virtual groups, the context in which *decision making* can emerge (Boursier et al., 2018). Shared information and experiences contribute to the construction of a *perspective know-how* in parents of ASDs children. Indeed, they have to learn how to cope with their child difficulties and, sometimes, how to manage their parental role. Obtaining this “knowledge”, they may feel supported in the management of the child’s and family difficulties.

The construction of a parental identity also emerged as a specific point of discussion (at both an implicit and explicit level): balancing roles and activities, re-organizing family planning, coping with feelings of ambivalence, shame and guilt, and many other difficulties must be faced (Manna & Bousier, 2018). A related problem also emerged concerning these difficulties: members sometimes identify each other through an internal similarity (belonging to the group) and an external dissimilarity (outgroup). The risk is evident here: the parental group tended to reinforce itself and the memberships’ identity through the difficulties all members face with their children, which might reinforce extreme opinions, leading an identification with the syndrome and its symptoms (Margherita and Gargiulo, 2018), and might even foster preoccupation about children.

5. Conclusions

This study contributes to understand how parents who participate in forum groups perceive their autistic child and how they deal with the challenges in parenting. According to Baum (2004), parents of children with special health-care needs may highly benefit from participating in a group in which people share the same difficulties. However, when developing new support interventions for parents of children with ASDs, researchers and healthcare professionals should consider the importance and the risks of peers’ support groups, especially the widespread e-groups. Moreover, our study might help in better understanding and defining the psychological and practical difficulties that the parents face in everyday life, so to promote interventions that are particularly focused on the parents’ real needs and that can help them in the development of better parenting abilities. Even though the qualitative analysis used in this study allowed a deeper understanding of the psychological themes that may recur in parents of children with ASD, the study has some limitations.

Firstly, the anonymity of parents reduces socio-demographic information availability. Secondly, the number of fathers in the forum was about one third of that of mothers. So, contents may reflect more maternal than paternal themes. Using a more balanced sample, future research could find interesting differences in how mothers and fathers use the online groups. Moreover, the lack of comparison with other e-communities of parents whose children display different disorders did not allow us to disentangle in the finding the general contribution of group dynamics from the specific contribution of the child's disorder. Another limitation is that some parental responses to disorder in children are culture-bound and are also related to public policies in the prevention, diagnosis, and treatment of children, so further examination in a culturally diverse group or in international forums is warranted. Even considering these limitations, the findings of this study based on a methodologically valid and reliable qualitative analysis support the view that e-groups allow parents of children with ASDs to perceive both social and emotional support, and to develop positive feelings of belonging that may help them in everyday life.

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DOI: 10.6092/2282-1619/2019.7.2104