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ORIGINAL PAPER

Parents' Perspectives Towards the Diagnosis of Autism: An Italian Case Study Research

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Abstract We investigated the parental changes and challenges that anticipated and followed the communication of the diagnosis of autism. The methodology was a collaborative and participatory case study focused on the perceptions of 31 families with a child on the autism spectrum enrolled in a no-profit Association in the Province of Monza and Brianza (Italy). The aim of the research was collecting information for the establishment of a local permanent observatory, monitoring the needs of families with children with autism, and identifying possible operational proposals to implement the quality of the territorial services, through the enhancement of the experiences, perceptions and representations of families, analysing their points of view. Methods included semi structured interviews and questionnaires; the data were analysed through the interpretative phenomenological analysis method. The findings show that parents need to be supported in order to avoid crisis and confusion on the child's future perspectives, as consequence of the diagnosis of autism. The paper draws out implications for further studies that wish to analyse other family perspectives.

Keywords Autism spectrum conditions · Diagnosis · Family · Association · Case study research · Interpretative phenomenological analysis

Introduction

Autism is a complex characterized by a deficit in social interaction and communication, the presence of repetitive and stereotyped behaviours and sensory issues, which, even if they occur in the early stages of development, characterise the whole person's life (Nuner and Griffith 2011). The challenges related to this condition engage not only the diagnosed individual, but also those who take care of him, first and foremost parents, relatives, teachers, specialists and the whole community (Mandell 2012; Nealy et al. 2012; Pozo et al. 2011). The family, as primary framework for each member and a fundamental social unit, should be the object of special attention from society, supported along in its growing path but also in the dealing with the education and development of their children (Maggiolini 2011).

The complexity of family needs with a child on the autism spectrum is remarkable (Banach et al. 2010; Greeff and Van der Walt 2010) and there are dedicated services that offer adequate support to parents who are left alone in dealing with this life path (Plumb 2011). Indeed, the impact of social support on parental resilience and stress in families with a child diagnosed with autism is significant. As described by Autism Europe, a European No profit association for parents, the autistic condition can be considered different from any other disability and its characteristics may cause an additional source of stress for parents and make it extremely problematic in the life of the whole family: The households left alone to face the difficult task of raising a child with autism should soon encounter stress and anxiety because of the misunderstandings about the nature of this disorder (Autism Europe 2001; Brennan 2011).

One aspect of major importance that contributes to the family balance and development is the ability to identify and draw its skills and strengths, considering internal and external resources. One of the main resources is certainly the family association reality, a form of solidarity and

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support, which in recent decades is acquiring a growing relevance and social visibility in Italy, also due to the financial crisis. The associative reality takes on a value and a meaning all of its own, especially in the case of households with children on the autism spectrum.

The present study starts from this perspective and aims at supporting the local and national associative activity, taking into consideration parents' voices and experiences as the main vehicle of information and resources. The investigation aims at understanding the family perspective in relation to the presence of a child on the autism spectrum. The main aim is to enlighten the changes experienced by the parents as results of the diagnosis of autism, in particular in the family, personal and work relationships. The researchers and the association referees were interested in examining in depth the experiences and feelings that accompanied the parental couple from the communication of the diagnosis until the present reality, highlighting the changes and the dynamics of interactions with the community and the network of services. The specific objectives of the study are: (1) Address the parents as a fundamental resource to evaluate the practices and experiences of inclusion of the child and identify possible future project developments; (2) Detect the level of satisfaction with the services of the families in the geographic area and investigate possible needs submerged in relation to the diagnosis of autism; (3) Increase knowledge and awareness about the effectiveness of health and support services that deal with the communication of the diagnosis; (4) Start to build a provincial database that documents the households' point of view with a child with autism, in relation to the quality of services offered, encouraging the creation of a network of solidarity between the institutions involved.

It was founded in 2008 by a couple of parents whose son was diagnosed with autism. The association's aim is to serve families with similar needs that deal every day with autism and its challenges, providing support and help throughout different services (therapy, counselling, self-help groups, case management and educational mentoring). The association serves 48 families and it is part of a network of 23 regional social agencies and providers (private and public educational, health and support services).

Method

Participants

The participants selected for this research are representative of the families with children with autism belonging to a No Profit association—namely 'Cascina San Vincenzo' (CSV)—active in the Province of Monza e Brianza, Lombardy (Italy), which serves families and parents with a child with autism spectrum conditions (ASC). The research sample is represented by 31 families, in details 28 mothers and 14 fathers, for a total of 42 persons: both parents attended the interviews and/or questionnaire together in 26 % of cases, the mother alone participated in 57 % of cases and the father alone in 17 % of cases.

The collected data enlighten some specific parents' characteristics. The sample majority is composed by married couples and in 20 % of cases the marital status changed after the communication of the autism diagnosis. As for the working activity, mothers are mainly employed in educational provisions and fathers are mostly regular or specialised worker. Also the family unit is relevant: eight parents have one child, 15 have two children and 8 have three children; the child on the autism spectrum is the eldest in 14 families, the second born in 14 families, and the third born in 3 families. This means that for 55 % of cases the child with autism was born after other pregnancies and the 26 % is an only child (with autism). 81 % of the participants' children with autism are male, aged between 4 and 10 year-old. All the couples are Italian, except for one emigrated from Congo.

Procedure

Through a multimethod approach has been possible to investigate the family perspectives and feelings on challenges and changes owing to the diagnosis of autism. The multimethod approach enabled the researchers to catch the complexity of the single case through a deep detailed analysis of selected aspects (Stake 2005). This methodological choice enabled a focus on the participants' points of views and perspectives on the family changes and challenges related to the child's diagnosis of autism. The study involved all the association representatives, through a collaborative methodology, and preparatory meetings were done before the data collection started.

In this research, specific actions were undertaken in collaboration with key members of the association and family representatives. It was necessary to use this methodology to analyse the different perspectives and to collect specific data on how the actions changed the daily practice of working with families having children on the autism spectrum. The research used a multimethod approach and explored the questions described above through semi structured interviews (19) and questionnaires (23): 39 % of the participants took part in both interviews and questionnaires, 22 % only in interviews and 39 % answered only the questionnaires.

At first the realization of a semi structured narrative interview was considered necessary in order to allow parents to freely express, and it provided flexibility in deciding what to share with the researchers regarding the personal history related to the diagnosis of autism and their feelings and emotions (Atkinson 2002). The semi structured interview was chosen because it allows the interviewees to fully express their experiences about a specific topic proposed by the researcher and deepen the aspects that result more interesting (Callini 2003). The track used for the interviews was built by the researchers in collaboration with the association referees and after a literature review. In details, specific preliminary focus groups were organized involving different professionals that serve the association (therapists, social workers, parent trainers).

The working group selected the main area of investigation and these topics were compared and declined considering the specific research setting. For each topic selected, guiding general questions were built and then used by the researchers during the semi structured interviews. Each interview has been typed and analysed through the interpretative phenomenological analysis (Smith and Osborn 2007) that guided the researchers in building the second research tool that is a questionnaire. The questionnaire was designed with closed, multiple and open questions, divided into six areas, respecting the original scheme of the interview, and with an introductory section devoted to collect participants' personal details. In this paper only the data referring to the first three areas will be presented, due to space and international relevance reasons. These areas are: the warning signs of autism seen by parents, the diagnosis delivery and the changes in the family, in relationships and at work after diagnosis.

Data Analysis

The qualitative data collected during the research were analysed using interpretative phenomenological analysis (IPA). This is an approach to qualitative research with an idiographic focus, which means that it aims at exploring in detail how participants are making sense of their personal and social world and it attempts to explore personal experience and perception of an event (Smith and Osborn 2007). A two-stage interpretation process is involved. The participants are trying to make sense of their world and the researcher is trying to make sense of the participants trying to make sense of their world. IPA aims to capture and analyse the meaning that participants assign to their experience (Reid et al. 2005). In this research, interpretative phenomenological analysis was fundamental to understand the households' experiences, giving meanings to people's perspectives and feelings on their daily life with children on the autism spectrum and the communication of diagnosis.

The quantitative and qualitative data collected through the questionnaires and the semi structured interviews were analysed using IPA. This involved reading and rereading the transcripts of each focus group and interview. Following this, the researcher undertook an initial textual analysis, focusing on the key themes arising, including conceptual comments. After this, the researchers identified the emergent themes arising from the participants and searched for connections across emergent themes. The researchers looked for patterns across themes and interpreted the findings on different levels (Smith et al. 2009).

Results

The findings will be presented through the analysis of quantitative and qualitative data collected with the questionnaires and the semi structured interviews, respecting the three areas of research: perceived warning signs of autism, the diagnosis and the changes occurred. The researchers analysed each question as a single variable, developing graphics to understand the percentage of positive and negative opinion in the answers and the topic trend. The main themes identified in the questionnaires were used as a theme guideline for the IPA analysis of the interviews.

Warning Signs of Autism as Perceived by Parents

The majority of participants (71 %) noticed the first warning signs of autism within 2 years of child's life and a third of parents observed them between the third and the 4th year. Only one mother reported to have noticed problems since birth. International studies have identified possible 'alarm bells' as already noticeable between 12 and 24 months of age, such as specific anomalies in leisure activities and exploration of objects (Morgan et al. 2008; Ozonoff et al. 2002). However, it is complex for the parents to observe and recognize clearly these signals before the 24 months, especially if it is the first child. Early identification of the autistic condition facilitates the path to diagnosis, making timely access to educational and therapeutic services (Frenette et al. 2011).

The main difficulties that parents have observed in the child can be divided into four areas: language, social relationship, behaviour, and body movement. The majority of participants (83 %) detected the first signs of the disorder in the area of *language* (delay or absence of speech, echolalia, repetitive phrases and words, abnormal or bizarre verbal expressions, speech block) and *social relationship* (isolation, not seeking a interaction with others, difficulties or lack of eye contact, lack of interest in relationships, detachment, emotional indifference).

In other cases (78 %), the signs are related to the *leisure area* (play activities are atypical, repetitive, stereotyped, not shared; child is not able to respect rules and turns).

Many participants (78 %) reported that they had the initial perception that the son was deaf or with *hearing problems* (not responding to his name, not reacting to clear and strong sound stimuli, not being distracted by noise). Indeed, some parents, in first instance, recurred to audiometric specialists to find a solution to the manifest problem because they thought the child was suffering from a hearing impairment.

Half of participants (52 %) noticed anomalies in the area of *behaviour*, that they defined "bizarre" (possessiveness towards certain objects, fixation, abnormal reaction to specific stimuli, hyper/hyposensitivity, sensory issues, hyperactivity, irritability, unjustified crying, behavioural regression) or problematic (self-injury, aggression, lack of impulse control, difficulties in managing frustration, inability to manage the tone of voice, inconsolable crying). Finally, 22 % of households have reported *sleeping issues* (difficulties in falling asleep, irregular sleep-awake rhythm, crying at night, lack of sleep) and delays in the area of *global and fine motor skills* (abnormal gait, walking on tiptoe, difficulties in performing motor exercises such as flips and jumps, slow acquisition of graphics skills). The difficulties encountered by the participants are in line with what it is already mentioned by other investigations (Bryson et al. 2007; Landa et al. 2007; Mooney et al. 2006; Morgan et al. 2008; Werner and Dawson 2005): atypical behaviour, difficulties in area of language, social communication, and leisure skills.

In the 72 % of the research cases, the mother was the adult person that recognised and pointed out the warning signs of autism, followed by fathers, kindergarten teachers, other family members (grandparents, uncles) and, in a smaller percentage, general or specialised medical practitioners.

The main theme that emerged from the semi structured interviews is related to the misperception and confusion felt by parents when the warning signs occurred and it was due to the uniqueness of the problem and the lack of knowledge of parents and community. The complexity of autism and its related difficulties were perceived as source of stress and anxiety in participants. The mother was the person that noticed the problems at first and she felt alone when the husband, professionals or relatives didn't give too much attention to her perceptions (see Table 1).

The Diagnosis

After noticing the first child's difficulties, most parents turned to specialists for more clarification, asking for a diagnostic path. Only in two cases, the family did not want to proceed in the search of clarifications. The reasons for

Table 1 Parents' perspectives regarding the first warning signs of autism

First warning signs	Parent's feelings	Other people's reactions
"The baby's development was initially normal but around 15 months this path was halted, and he could not speak anymore and communicate with us as before"	"I was very worried because I couldn't find any reason to the many issues in speech and behaviour that were occurring"	"The paediatrician thought was too early to investigate because the baby was too young, so initially we did nothing but I was very worried"
"[…] He began to display a number of problems that completely isolated him, like not looking anyone in the eyes; he wasn't independent in the hygiene and he was screaming in an incredible way and he was frightened by any kind of noise, in particular from TV commercials"	"We had the comparison with her sister and some things were appearing out of tune: is it true that every child has his times but he was too different and we didn't know what to do"	"From the moment I've notice the warning signs, it has been started the strong disagreement with my husband: I thought this way of playing was monotonous and inadequate, my husband didn't. For him, there was no problem at all"
Our journey began about 17 months, because he wasn't able to speak. It was followed at first by the local Neuropsychiatry and they did a series of tests, from which it appeared that he was healthy. At the very beginning we thought he was deft"	"[…] After knowing that actually he didn't have any hearing problems, we made further investigations because we were so worried and scared about his problems"	"Our general doctor told us to not to worry about the baby's problems because it is normal that children cry so much and have sleeping problems, but we still felt that something was wrong"
"We became aware of the first signs when she was 2 years old, at the beach, because our little girl did not try to play with others and she was always playing one game: collect the sand and throw it into the sea. If we didn't change this play activity, it would go on for hours"	"I felt very alone and sad. I was so scared that she didn't want to play with any other children, it was like she couldn't see them"	"I spoke about it with the kindergarten teachers but they didn't notice any signs, so I thought I was too anxious and I was seeing problems everywhere"

this choice are essentially due to the lack of confidence in the doctor who had addressed the issues at first.

In details, half of parents have made the decision to go further in the investigation through a diagnostic path without consulting any specialists before; others followed the advice of professionals or listened to teachers' suggestions. No one received indications from friends or relatives. From the data collected through the questionnaire, it emerged that the diagnosis has been obtained when the child was between three and 4 years old; only three children received the diagnosis at an earlier time and five children did it after the age of five. A third of the children (32 %) received the diagnosis of autism about a year after the recognition of the first warning signs, and the 39 % received the diagnosis between 18 and 36 months after.

The participants' perceptions about the style of communication of the diagnosis are very heterogeneous and unique for each parent. The positive aspects are the relevant expertise (52 %) and the empathetic and sympathetic attitude of the doctor (23 %). Further positive perceived aspects highlighted are completeness of information, ability to listen and reassure the parents and sureness about the topic told. The negative aspects are reported by a smaller percentage of households and they primarily involve the doctor's incapability to provide future perspectives at the moment of communication of the diagnosis (19 %), the conversation was unclear and the diagnosis not sure or complete (19 %).

During the communication of the diagnosis, half of the participants (48 %) received detailed information about specialized centres and treatment programs (for example: use of Alternative and Augmentative Communication, PECS, TEACCH approach, speech therapy, psychomotor therapy, behavioural therapy). After receiving confirmation of the diagnosis, the participants decided to talk about it especially with teachers (93 %) and family (maternal and paternal grandparents). Half of the parents spoke with some friends and a third with the colleagues. Only in one case, the diagnosis was not disclosed to anyone.

The main theme that emerged from the semi structured interviews regarding the communication of the diagnosis of autism is related to the struggle to reach out the answers they were looking for about their child's conditions. The communication of the diagnosis was done in many different ways and it depended uniquely on the specialist's communication style and empathy. Indeed, the participants' experiences enlighten how important was the moment when the diagnosis was delivered and they discovered that their child has autism. The feelings experiences were many and various and some participants expressed what they felt at the communication time as a mix of different emotions, both positive and negative (see Table 2).

Table 2 Parents' perspectives regarding the communication of diagnosis

Positive perceptions	Mixed perceptions	Negative perceptions
"The communication was very clear and direct, (the doctor) told us right away out of our heads some strange ideas about autism because today the word "autism" has become a container of possibilities is much larger than 10 years ago, into which very functional and behavioural disorders and the child could not be seriously compromised"	"When she got the diagnosis, on one hand I felt a little relieved because in this way we understood what the child's issue was, on the other hand we felt out of control because we did not know how to behave and how to handle this new situation. We've never heard about autism, but we knew we had to do more and we needed to understand how to do it"	"During the communication of the diagnosis, my husband and me were present. That time was very dramatic: the doctor did not want to expose himself and he didn't want to say the word "autism". I did it. It was like living a self-fulfilling prophecy because I had already suspected that it was autism, through the Internet. It was very hard to accept the diagnosis because in that moment I felt as if I had facilitated the doctor to say that my son has autism"
"The doctor was competent, comprehensive, he was keeping reassuring us about the positive things of having a child with autism" "The way the doctor told us the baby's diagnosis was very soft and kind. We felt very welcomed in his office and we had the right support to go over that bad moment. Every parent should have an approach like the one we had"	"The doctor that delivered the diagnosis was very capable and gentle, but initially we were floored. After a shock there is the phase in which you do not want or to hear anything, you do not want to listen or to ask for anything. We were feeling so. Then we started to look for something on the Internet: I found many services that could help us and I felt a little bit better"	"At the time of the communication, doctors have assumed that we knew already what our son had […]. The diagnosis was totally out of the blue for us. The doctors then proposed a path to check certain aspects, so we felt alarmed because we did not know if there would be other problems beyond autism"

The collected qualitative and quantitative data enlighten that this time is very significant for the family history and quality, content, places, methods and type of professionals involved in the communication process are crucial elements to enable parents to properly understand the diagnosis and empowering their resources to develop new perspectives: This has been confirmed by other international researches (Riddick 2008; Keenan et al. 2010).

Changes Occurred in the Family, in Relationships and at Work After Diagnosis

The majority of participants (89 %) declared that the child's diagnosis has led to significant changes, especially within the couple's relationship. The change was felt as positive for the 30 % of those who responded; in details it had positive referred positive effects for the couple, in terms of harmony and affinity between parents. For 59 %, the negative effects are: misunderstandings and subsequent detachment in the couple (43 %), isolation of the family from the rest of the community (8 %), or less attention to the siblings in order to take care of the child with autism (8 %).

Then, it was asked if the changes had occurred in the relationships with the extended family and relatives. The 20 % of participants responded negatively, while the 23 % said they had received support from family members, especially grandparents, aunts and uncles, and they set out to offer their help in the management of children with autism and any other children. Some parents weren't able to get any support from family members (18 %); others believe that relatives express difficulty in understanding or accepting the specific condition of autism (38 %).

In the relationship with friends, the 24 % of participants said they had not perceived any change, while the 21 % felt they have been helped and supported by friends. A third of parents have started new friendships with other families with children on the spectrum. A smaller part of the sample had ended some friendships.

After diagnosis, the work of mothers has undergone major changes (in 74 % of cases) than that of fathers (45 %); 48 % of mothers and 42 % of fathers were required to benefit from the Italian Law for the Inclusion of Persons with Disability (Law 104/1992) that allows to care of a person with disability and take time off from work and care about their child, also through an economical support. Only a mother had to stop working and a father changed his job.

The main themes that emerged from the semi structured interviews regarding the changes in the family and its relationship network are different and various (see Table 3). The diagnosis has brought changes in the whole family dimension and the participants' perception of the problem is different in relation to the support offered by relatives, friends and colleagues. Most of difficulties felt by parents are related to the communication of the diagnosis of autism to closed relatives, like grandparents, that could be hurt and confused because they can't understand the complexity of the problem. In fewer cases, the same communication difficulties were felt with friends and colleagues. Friendship was felt as fundamental to maintain a social status and a contact with the local community and some participants enlarged their friend's network also thanks to new connections foster in autism services.

The findings show that the employer demonstrated unexpected understanding about the new situation and this empathy was believed to be very important for the family quality of life. In synthesis, some participants affirmed that many changes occurred after the discovery of autism and the delivery of the diagnosis, in particular they report lack of personal space, difficulties in relationship with the partner, communications issues and challenges in understanding and accepting autism. In many cases, however, the married couple becomes closer and more willing to share the problems and difficulties emerging in living with the child with autism, involving the relatives. Similar experiences are quoted in other researches and report (Myers et al. 2009; Oprea and Stan 2012).

Discussion

The findings have shown the uniqueness of the analysed local community but also how the family experiences are in line with other international researches. Indeed, it possible to discuss each analysed area and enlighten further impact on association and local services, based on the research results. This study has shown that the person who has perceived before others the *warning signs of autism* is the mother followed by the father, teachers and doctors. Therefore, the parents, though they are still inexperienced in the field of autism, are the first to notice that "something is wrong" in the child. In some cases, as revealed by the interviews, the paediatricians and other medical practitioners reassured the family, justifying the difficulties of the child as "typical differences between children from the age of development" or declaring "normal for some children to develop language or fine motor skills later than others."

This result enlightens, as obviously expected, the unique capability of mothers and fathers in caring and understanding their baby's needs and difficulties. It is relevant to consider the role of teachers and doctors, working in the early childhood educational services: This study shows how these professionals, if properly trained on autism, can sustain parents in the path toward the diagnosis. This means that family associations are asked to follow this path in different ways, as guiding parents in understating the problem and training professionals on autism and family needs, through fulfilling structured meetings where the parent is listened to and supported and are able to exchange views and perspectives with professionals.

The following aspect that has been discussed in this study is the *communication of the diagnosis* and its delivery to parents. This research has shown that the majority of parents, following the first warning signs, chose to be

Table 3 Parents' perspectives regarding the changes after the diagnosis

	Family	Relatives	Friends	Colleagues
Positive changes	"Between me and my husband, after the initial hit, there is a feeling of total cohesion and support"	"We have involved all our relatives; in particular the grandparents help us a lot. For 3 years we have been doing therapies and they have always took care of the child, otherwise we can not work"	"The friendships have increased, even with this problem, we found other families who live in the area and have autistic children, we meet often"	"The co-workers try to reassure me, minimizing the problem. Now, they always ask me about my child and my family and offer their precious help"
	"We always supported each other: when one of us is depressed and remotivate because all the problems, the other keep high spirits and energy for both"	"They helped us in any way, for therapies, and more. These things matter: knowing that you have your back covered matters so much"	"We didn't loose any friend. We have always talked clearly about what we felt and they have lived these steps slowly, with patience, next to us, without any prejudice"	"My boss understood immediately my situation and now is very supportive and allows me to take time off anytime is needed. This was a positive surprise"
Negative changes	"Between us there is an obvious lack of personal space for both spouses, and denial of married life. You are not able to do most of the outputs and there is no time to spend alone together. We are dedicated entirely to children with disorders in the balance of care for the child with autism"	"We are alone here, the relatives are far away and nobody can really help us on a daily base"	"Friendships have fallen apart because there is no time and our social life has changed. I have the feeling that people are mean with us and we feel alone"	"I had to ask for a part time job to be able to care about my child, and this wasn't good for my employment position"
	"The main change was the separation because of the absolute lack of his father: for him it was too difficult to understand and accept autism"	"Not all the relatives know that our child has autism because they don't live closed to us. This situation is unusual but not experiencing the problem makes them struggling to understand it"	"Some friends disappeared, they were probably scared of autism, but we didn't care"	"Sometimes I am not able to organise my day, facilitating the balance between my job and my child. Not everybody understand it at work"

proactive independently and along heterogeneous paths. There are many who have sought answers to their questions and concerns surfing the Internet. Access to the services of Child Neuropsychiatry occurred through different ways: Some parents have followed the advice of the doctors consulted previously; others have searched the web for the most suitable structure or have asked to relatives and acquaintances for information. There has been little reference of paediatricians providing the right guidance to the family and this is an important sign of the role that specialised doctors should have in the path to diagnosis.

To avoid parents' confusion and disorientation, family associations should be immediately reachable and accessible, without waiting lists, and the provided support have to be known in the community, preventing the tendency of searching the Internet to seek answers that are often wrong and misguided. The main associative mission is not to leave parents alone in the path of autism and advocating them in what it must be done for their child.

The findings have shown that the communication of the diagnosis represents a very important moment (Banach et al. 2010; Hastings 2008). In this emotional complexity, the parental couple should therefore be able to cope with the experience of pain generated by the traumatic event, identifying the ability to make sense of what happened, accepting the inevitability of the present situation and reaching in overcoming initial perception of complete impotence. Some participants describe this delicate phase of communication as a very intense moment, also because of the multiplicity of conflicting emotions. The majority of parents reported the positive aspects found in the communication style adopted by the doctor, who was competent, comprehensive, inclusive and reassuring: This element is fundamental for the family and a negative experience lived during the communication time can have a severe negative consequence on the family strengths and affect the projecting capability for the future.

Family associations should work on building a community network with health care professionals and advocating them for delivering the diagnosis through proper communication strategies, understanding the parents' emotions and expectations. Specific training on autism and parent training could be delivered to doctors and their work can be tuned with the association programmes, offering a multidisciplinary and proficient setting of experiences at the service of families.

Finally, this research has deepened the *changes in family life and relationships after the diagnosis*. The importance of parental support is especially clear when an emotional lack is perceived (Banach et al. 2010): This is particularly true for those families who have moved from a different region and due to the considerable geographical distance cannot benefit of the help offered by grandparents or relatives. If difficulties don't arise in the initial communication of the diagnosis to the group of friends and colleagues, then they can become a valuable resource. The child's condition, in some cases, led to the emergence of new friends. Parents who are able to recalibrate family dynamics, including through the support of the network of relatives and friends, maintaining a link with the community, seem to give a different vision of the experience and their ways of communicating and reaching out to others.

In few cases, drastic changes were required in the professional area, especially with regard to the activities of the father, while the mother had often rearrange time and place of work, resorting to the benefits of the national law 104/1999. About a quarter of mothers are housewives, however, this data cannot be put in relation with the presence of a child with autism. Only a mother stopped working after receiving the diagnosis. The effect of autism on mothers is higher than on fathers, as confirmed by other investigations (Baker and Drapela 2010).

In the interpersonal dimension, the family may reduce social contacts. It is especially at this time; however, it becomes particularly important to be able to find ways to express their feelings through appropriate relationships, with formal and informal supports (Papageorgiou and Kalyva 2010; Plumb 2011; Solomon and Chung 2012). Parent training and consultancy are the first kind of care that family associations should provide because the function of support and assistance to parents that share very similar experiences is of great importance in the local context and the associations have to start their support services listening and understanding the family needs.

The counselling can be declined in a community dimension, through parent training and self-help. The group dimension, which is essential for every human being, thus acquires a higher value when the link between its members is represented by experiences of struggle and crisis: The group becomes the place where the family is listened and respected, in cooperation and solidarity with the community providing support and solutions. It is clear, therefore, that family associations cannot be reduced to a group of people that share similar interests and life challenges, but rather constitute as an effort to validate the social nature of the individual and to respond to a primary need for participation, care and responsibility.

In synthesis, the results achieved showed the importance of parental couple's emotional, relational, economic and organizational stability. The findings arise, then, a subsequent research perspective: investigate the dynamics of the couple, their coping skills, and deepen the analysis of many changes that have occurred in the presence of a child with autism. Therefore, siblings are directly involved in the growth of the family group. In the present research were not taken into consideration their experiences and perspectives, which could be understood through qualitative and quantitative research tools similar to those already used in this research. Using the same methodology and tools already defined (semi structured narrative interview and questionnaire), it is possible to enrol an investigation involving a bigger group of families selected through a systematic sampling and therefore representative of a specific geographical area (provincial, regional or national). The data obtained could greatly strengthen those currently identified and allows a more detailed analysis in relation to the family's experiences and their relationship with the services offered by the local network.

The findings allow services professionals to develop new perspectives and operational support, confirming the importance of accompanying educational practice with social and pedagogical research paths. The research has shown how important is recognising to the family the ability to activate the positive resources after the diagnosis of autism, even thou it is a stressful and dramatic moment: This is possible only if the community is able to supports households. The discovery of autism often stops the emotions and blocks the parents' capacities. During the research, there was the opportunity to learn about different ways to be parents and to cope with the condition of autism: Many participants testified the positive experiences that stemmed from strength to fight and to continue to seek what can be achieved to improve the quality of life of their child. Others, however, find difficult to abandon feelings of disappointment and helplessness and are united by a substantial mistrust, in part associated with the trauma resulting from the discovery of autism and in part fuelled by the disappointment and the perceived inability to seek and receive help. In conclusion, it is fundamental to recognise the role of local services that support every day parents and their children on the spectrum in the path of life. The commitment of local associations in close cooperation with social and health services is a prerequisite to the construction of a common and proactive dialogue able to raise family support and awareness on Autism spectrum conditions.

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