

Autism spectrum disorder and parents' daily life: Social challenges and personal perceptions within an audiovisual therapeutic treatment

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Abstract

Our research aims to explore the impact that the diagnosis of autism spectrum disorder (ASD) may have on the emotions, perceptions and daily life of parents of children with ASD Level 1, according to the Fifth Diagnostic and Statistical Manual of Mental Disorders. This study stems from a pilot project – Video-Pharmakon – developed by Azienda Ospedaliera San Giovanni di Dio e Ruggi d'Aragona (Salerno, Italy), in the Clinical Unit of Therapeutic Filmmaking and Documentary Videotherapy for Neurodevelopmental and Autism Spectrum Disorder. Video-Pharmakon project involved two pairs of parents and their child with ASD. Because scholars believe that the family system plays a key role in the success of children's therapeutic processes, in parallel with the children's course, we decided to reserve a great deal of space for videotherapeutic parent training, involving them in interviews designed to explore their perceptions related to ASD, parenting skills, and the couple's relationship. The interviews were videotaped, transcribed and analyzed through a multidisciplinary and qualitative computer approach. According to the literature, the diagnosis of ASD significantly affects parents' lives, which revolve entirely around their children, especially that of mothers. The data collected can therefore be useful for implementing parenting support interventions and improving the well-being of children and parents.

Keywords: Autism spectrum disorder; Therapeutic Filmmaking; Videotherapy; Qualitative research method; Text mining; Sentiment analysis; Text analysis.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social and relational deficits. As reported by the American Psychiatric Association (APA, 2013), ASD is defined by the presence of impairment in the areas of social interaction and communication, as well as the presence of restricted and repetitive behaviors. People with ASD report difficulties in developing peer relationships, sharing experiences and communication, show little interest in others and less capacity for pretending or symbolic play, have restricted interests, tend to follow an inflexible routine, in their daily lives, and express intolerance toward change by reacting with distress, opposition and aggression. Several studies show a higher level of stress in parents of children with ASD than in parents of children with other developmental disorders (Alenazi et al., 2020; Lee et al., 2024). However parents of children with ASD who can rely on social resources and support are more likely to manage educational difficulties and experience lower levels of stress (Bent et al., 2023). Regarding gender differences in the implementation of coping strategies in response to stressful events, scholars demonstrate the existence of different coping strategies between men and women, considering men more competent than women in avoiding stress (Graves et al., 2021; Theodoratou et al., 2023). These findings could be interpreted by considering the different roles men and women tend to play in family

management and child care (Reshi & Sudha, 2022). In particular, in families with disabilities, women seem to be more likely to be the designated caregiver and to mediate between the family and physicians (Gilmore-Bykovskiy et al., 2018; Pillemer et al., 2018; Schaffler-Schaden et al., 2021). Vadivelan et al. (2020) also highlighted gender differences in the attribution of meaning to illness and disability, reporting that women are more likely to blame themselves for their children's problems and to experience the disorder and disability as a threat to their identity. In the case of children with ASD, the characteristics of the disorder influence and change several aspects of parenting, often requiring the assumption of multiple roles and the implementation of new and more complex coping strategies (Saladino et al., 2021). Parenting a child with ASD, in addition to entailing greater responsibilities, can also generate ethical dilemmas, a sense of inadequacy, frustration, and various relationship problems. Children with ASD need more guidance, supervision and support than typically developing children, which entails a large investment of time and resources on the part of the family. In responding to children's needs, parents should acquire new skills and strategies (Sabatino et al., 2020; Saladino et al., 2021). Parents tend to give up everything in their personal, couple, social, and often work lives to focus exclusively on the needs of their children. As a result, they may experience loneliness, isolation and imbalance in the couple relationship (Markodimitraki et al., 2024). A common risk for families relating to disabilities or

neurodevelopmental disorders is the progressive reduction of communication and affectivity within the parental couple who tend to recognize only the parental role, ignoring the couple and negatively affecting the marital relationship (Ratri & Ratnasari, 2023). An additional challenge that parents of children with ASD face is stigmatization in the social context. Indeed, because of their difficulty in social behavior, these children tend to transgress social, spatial, or temporal boundaries (Alshaigi et al., 2020). Indeed, children may exhibit inappropriate social behavior, increasing the embarrassment, fear, distress and anger of parents who are faced with the “double duty” of managing their own feelings and emotions and the reactions or judgments of others. Indeed, children's failure to comply with social norms is attributed to parents' inability to educate and instruct them. In this context, parents often respond by scolding their children in public or by internalizing moral responsibility and developing self-stigma (Ibid.). According to the literature, intervention strategies for families with children with ASD should focus on developing social and communication skills, reducing the severity of children's dysfunctional behaviors, and increasing parental support (Dawson-Squibb et al., 2020; Deb et al., 2020; O'Donovan et al., 2019). In particular, parenting training has been shown to be highly effective in improving children's responsiveness, expressive language, and functional play and reducing behavioral difficulties, as well as improving the social and coping resources of the parental couple, thereby increasing their ability to provide

appropriate care for their children (Saladino et al., 2020). Based on these considerations and assumptions from the literature, the present study aims to increase knowledge on the topic of parenting, specifically to explore how parents of children with ASD tend to perceive their role and relationship with their children and cope with the difficulties and challenges associated with the disorder, with a focus on exploring gender differences in coping with stressful events and emotions associated with ASD. As for children, the aim is to improve their social, emotional, and interpersonal skills, supporting them in perceiving and recognizing their own emotions and feelings and improving their ability to share and communicate them effectively to others, with the ultimate goal of improving the quality of life for both parents and children, providing more targeted guidance and suggestions to researchers, clinicians, and other professionals working in this field.

The Project

Our work derives from Video-Pharmakon pilot project developed by the San Giovanni di Dio and Ruggi d'Aragona Hospital (Salerno), in the Clinical Unit of Therapeutic Filmmaking and Documentary Videotherapy for Neurodevelopmental and Autism Spectrum Disorder, in collaboration with the Department of Political Science and Communication of the University of Salerno; the Department of Human, Social and Health Sciences of the University of Cassino and Southern Lazio; the Department of Medicine, Surgery and Dentistry “Salerno

Medical School”; the Laboratory of Audiovisual Storytelling (LABSAV) of the University of Salerno; the Department of Medical and Surgical Sciences “Magna Graecia” of the University of Catanzaro; the Institute for the Study of Psychotherapies in Rome; the socio-cultural association “Gruppo Pensiero”; the socio-cultural association “Sviluppo Psicosociale”; “Psicotipo,” Association for Information and Updating in Psychology; and the Society for Research in Video and Filmmaking Therapy (REFIT). The present study involved two Italian male preadolescents, ages 11 and 13, diagnosed with high-functioning autism spectrum disorder (HFASD-Level 1), a moderate form of the disorder characterized by near-normal language skills and intelligence but social and behavioral impairments. The sample, including the two children and their parents, was recruited from the San Giovanni di Dio and Ruggi d'Aragona Hospital in Salerno, Italy, specifically from the Clinical Unit of Therapeutic Filmmaking and Documentary Videotherapy for Neurodevelopmental and Autistic Spectrum Disorder (Italy). The research team included a neuropsychiatrist, a psychologist-psychotherapist, a sociologist, and a filmmaker. As needed, the protocol included the involvement of other professionals to support the participants and professionals, such as educators, communication facilitators, and assistant directors.

Video-Pharmakon pilot project analyzed is based on a therapeutic intervention implemented through the use of audiovisual tools. With regard

to the experimentation of these tools in therapeutic contexts, reference can be made mainly to the arts therapies, of which cinematherapy, documentary videotherapy and therapeutic filmmaking constitute some of the techniques that employ audiovisual language as a tool to raise awareness and promote change.

Documentary videotherapy is based on the patient's observation of his or her own therapeutic sessions. In this process, the patient is not a passive observer of an unfamiliar narrative, but rather the protagonist of his or her own life story reproduced on a screen, which can be viewed and reviewed, confronting different and sometimes unseen images of self. This technique allows for an unraveling like that operated by the mirror reflecting the individual's face, showing the patient a fundamental part of self that would be impossible to observe without it, allowing the patient to explore and interpret the reality he or she experiences from perspectives other than the usual ones. Cinematherapy presents itself as a process of redefining the setting, with the therapist working to recreate those environmental conditions by which the patient feels immersed in the story as if at the movie theatre, involved in a collective vision together with other patient-spectators. In a different dimension from those previously analyzed, therapeutic filmmaking is based on the creative participation of patients' biographical or fictional stories (Cohen et al., 2015). This technique involves participants telling their own story through video, simultaneously becoming scriptwriters, directors and actors of their own

film. The conception, construction and interpretation of the film represent the actual therapeutic process during which, through autobiographical and participatory storytelling, the patient is the first-person promoter of his or her own path of change (Sabatino, 2019, 2023, 2024). All these audiovisual resources are used at the same time as therapeutic support for patients and analytical material for researchers, as well as for the editing of the videomedications, administered during the therapeutic process. After the assessment phase, consisting of interviews and administration of questionnaires, the two children are involved in creative and playful activities with the aim of leading them to create their own film, of which they become scriptwriters, directors and editors thus perceiving themselves as protagonists of their visual narratives. The cognitive and emotional mechanisms associated with self-representation and storytelling in pictures enable participants to portray what is difficult to describe with words, giving them the means to express themselves and their own voice by interpreting them, incorporating them as happens during children's play. This process of self-description has a therapeutic effect in that it works on a double step, the construction of one's real story, with narrative tools particularly drawings and stories, and at the same time the assumption of the identity, emotions, thoughts and words of one's alter-ego, representing themselves, based on how they perceive themselves, and their heroes, based on how they imagine and construct them. The two steps are

reinforced by the use of video tools that allow them to transform stories, drawings and games into a real film in which children are scriptwriters, authors, directors, cameramen and actors, experiencing all the steps related to film editing that overlap with the representation of their perceived personal identity and story and the construction of the new identity they would like to assume and the story they would like to live (Sabatino, 2024; Sabatino et al., 2021). The final narrative becomes the main outcome of the therapeutic journey. The audiovisual team guides the children during all stages of film making by teaching them how to use audiovisual tools, such as the camera, laptop and related instruments, and how to scan and organize the various activities of film construction and making, without intervening in the design and interpretation of the film by letting the children freely manifest their ideas, preferences and imagination. At the same time, the psychological team intervenes to stimulate children to explore their limitations and difficulties and to improve their emotional reactions and social skills, particularly with the aim of increasing their autonomy, self-esteem and self-efficacy, and facilitating communication with other children and team members. First, the group explains the rules of communication to facilitate the children to work as a team and support each other during the writing of the plot and all stages of making the film. The film plot, supported by the whiteboard, follows four main categories: characters, actions, desires and fears. Participants use colored markers to draw their storyboard,

gradually filling in the different categories. Children make their respective films, alternately playing the roles of protagonists, directors and actors. They choose scenes, build the storyboard and focus the story from their personal interests and learn to share and consider the partner's perspective. This process leads to increased interpersonal skills, flexibility, responsibility and autonomy. In addition, according to the peer-buddy approach, participants use the partner to receive feedback on their perceived identity, and this further enriches the process of building and defining their new identity (Sabatino & Saladino, 2023). After completing the storyboard, participants decide on settings and arrange subsequent meetings to film the scenes included in the storyline. This process, called filmmaking therapy, consists of four sessions followed by two more meetings during which participants select the main scenes to edit their film. In these final meetings, participants are encouraged to share ideas and opinions, defining the meaning of the scenes and focusing on the main features of the plot from a visual and emotional point of view. The final version of the edited film is shown in a movie theater in the presence of the participants, their parents and the team. The viewing of the film is followed by feedback from parents and children who comment on the experience and share their emotions. According to systemic and strategic psychotherapy approaches that view the individual/patient as part of his or her social context and family system highlighting the mutual influence among its members and the profound influence of family

interactions and communication on the outcome of therapy, particularly when the patients are children, we decided to give great space in the therapeutic process to the parents of the two children, therefore parallel to the therapeutic resumption with the pair of children, the team involved the parents in a training consisting of 4/5 meetings over two months. Based on the assumptions in the literature that reveals that the role of the family, particularly the parents, is crucial in the well-being of children especially in the presence of neurodevelopmental and/or psychological disorders, it becomes useful for research and clinicians to act on the family system directly or indirectly to promote mutual change and improve the well-being of all its members. Thus, our work focused on family support with the goal of leading a pair of parents to focus on their relationship and explore their feelings, emotions, and family dynamics. Another aspect of this work was to provide parents with specific educational tools and strategies to understand their children's emotions and behaviors, thus respecting their identity despite the disorder. They choose scenes, build the storyboard and focus the story from their personal interests and learn to share and consider the partner's perspective. This process leads to increased interpersonal skills, flexibility, responsibility and autonomy. In addition, according to the peer-buddy approach, participants use the partner to receive feedback on their perceived identity, and this further enriches the process of building and defining their new identity. After completing the

storyboard, participants decide on settings and arrange subsequent meetings to film the scenes included in the storyline. This process, called filmmaking therapy, consists of four sessions followed by two more meetings during which participants select the main scenes to edit their film. In these final meetings, participants are encouraged to share ideas and opinions, defining the meaning of the scenes and focusing on the main features of the plot from a visual and emotional point of view. The final version of the edited film is shown in a movie theater in the presence of the participants, their parents and the team. The viewing of the film is followed by feedback from parents and children who comment on the experience and share their emotions. Another objective was to provide the parents with resources for their individual and couple well-being, which would enable them to reduce the parental stress associated with coping with the disorder and to regain their individual identity, interests, social relationships and professional growth, and to improve the couple relationship by increasing communication and empathy with each other, especially by trying to balance the maternal and paternal roles, making the father more present and attentive in the care of the children and consequently relieving the mother of family tasks and responsibilities.

During the parent training, the psychotherapist, in collaboration with the other professionals in the team, uses audiovisual techniques to help parents develop a greater awareness of family dynamics, explore their relationship with each

other, and recognize their feelings and emotions, with the aim of improving their parenting resources and strategies. Participants (parents and children) fill out questionnaires at the initial stage and then as follow-ups to monitor their achievements, one month, three, six and 12 months after the end of the therapeutic process. At each follow-up, the team conducts a 60-minute interview with each pair of parents and their child, videotaped by the director, in which the psychotherapist collects data to compare the results and assess the possible risk of losing the improvements achieved through the therapeutic course. These interviews represent the qualitative analysis on which the present study is based, which aims to investigate how parents perceive their respective roles as mother and father of children with ASD.

Materials and Methods

Participants

The study included two families consisting of a father, mother, and child with ASD identified and recruited from the San Giovanni di Dio and Ruggi d'Aragona Hospital in Salerno, Italy.

Procedures

This research was conducted in accordance with the international guidelines of the Declaration of Helsinki and the Italian Association of Psychology (AIP) and was approved by the Institutional Review Board of the Department of Human Sciences, Society and Health of the University of Cassino and Southern Lazio (Italy) and the Campania Sud Ethics Committee of the University of Salerno (Italy). Participants signed

informed consent forms. At all stages of the research, the privacy of participants was guaranteed. No prizes or compensation were granted.

Statistical analysis

The qualitative interview, formulated by the team's sociologist and psychologist, investigated the following elements of the parenting experience: (a) daily organization; (b) perception of one's maternal and paternal role; (c) perception of ASD; (d) child-parent relationship; (e) couple relationship; and (f) perceived social support. The interviews, lasting an average of 60 minutes, following the guidelines provided by the Jefferson Transcription System, were videotaped and transcribed verbatim, then analyzed and compared.

The data from the interviews were subjected to three different analyses, each with specific tools and fields of inquiry.

The first analysis, called Topic analysis, was conducted jointly by the sociologist and the psychotherapist, through a selective highlighting approach using R-based Qualitative Data Analysis (RQDA) software, which enabled them to identify and code the themes and structures that emerged from the interviews by isolating phrases or groups of associated phrases. Five main categories emerged from this method of analysis.

The second analysis, known as text mining, was based on natural language processing systems. Specifically, text mining procedures were applied to each interview to extract recurrent terms and

attribute meaning based on the context of the parenting experience.

The third analysis is a linguistic analysis called Sentiment analysis, a computerized procedure that can assess the sentiment of the parenting experiences that emerged from the interviews and draw an appropriate comparison regarding both parental couple and gender.

R-based qualitative data analysis

RQDA is a qualitative analysis package that can be installed and run in the R system. Developed by Huang Ronggui in 2008 as a free CAQDAS application (Huang, 2014), it allows the user to work through interfaces based on graphical icons and visual indicators, rather than syntax. RQDA allows textual data to be loaded and treated as units of analysis; large datasets can be recorded, stored, indexed, sorted, retrieved, and visualized. The software ensures flexible coding and provides maximum transparency of the research process, which can be tracked at all stages by other researchers who can control how cases (data attributes) were classified and how data were coded and analyzed, increasing the rigor, validity and replicability of qualitative research. RQDA can also transform coded results into HTML files, increasing the ability to share data and facilitating keyword searching.

Text analysis was used as the primary research tool to explore and interpret the experience of parents of children with ASD. The text of the interviews was gradually coded into 37 first-order theoretical dimensions that were then aggregated into 5 main dimensions. An inductive type of coding was used that involved textual

units (sentences) based on established concepts, variables and/or theories. In the coding activity, the team's sociologist and psychologist paid attention to “coding traps” (Gilbert, 2002) that can lead to de-contextualization of data, and to “flexibility of coding” (Friese, 2011), understood as the constant activity of comparing and improving coding labels to represent the issues raised.

Text mining

Text mining is a form of data mining in which the data consists of natural language texts, i.e., “unstructured” documents, which combines linguistic technology with data mining algorithms. Unstructured texts require extraction analysis to be converted into structured form. Text mining employs a multidisciplinary approach using information gathering, information retrieval, text analysis, information extraction, clustering, visualization techniques, database processing techniques, machine learning techniques, and data mining. In our study, text mining analysis is based on partitioning text into individual words weighted or normalized in various ways.

In general, text vectorization allows words to be transformed into a computer-understandable numerical standard and then indexed, that is, moved to a list of relevant words through a series of procedures. Text searching based on the basic unit of words allows the application of some of the most common text mining procedures, such as topic analysis and sentiment analysis, applied in our study with the open-source software Rstudio.

Topic analysis

The first step in identifying thematic words within interviews is normalization of text documents, also called text preprocessing, which involves several steps: text tokenization (division of text into words); removal of stop words (empty and meaningless words, such as conjunctions or adverbs); stemming and rooting (reduction of word roots); normalization (removal of typos and conversion of upper to lower case, removal of excess numbers and spaces, and punctuation); and structure recognition (identification of sentence boundaries, prepositions, periods within complex sentences, and word boundaries themselves). These steps are functional for automatic processing for term-document-matrix (TDM) creation. In the vector-spatial model, the text is analyzed according to the words that compose it.

Text preprocessing was performed on all documents, a list of all words used at least once in at least one interview was created, and all terms used only once in a single interview were removed. Each document is represented as a vector of numbers; a collection of documents will then be represented by a two-dimensional matrix in which each row corresponds to a document and each column to a word. Each element of the matrix is represented by an integer, most often equal to 0, indicating the frequency of the term in that document. In the Terms-Documents-Matrix we find in the rows the words and in the columns the documents in which the respective frequencies are contained;

from this matrix the 25 most common terms by parent pair and gender were extracted.

Sentiment analysis

Sentiment analysis is one of the most widely used applications of text mining for natural language processing. Sentiment analysis is based on labeling a sentence or a small paragraph. Specifically, two lists of words are used, one positive and the other negative, which are compared with those contained in the body of the text by assigning a positive or negative label to the texts based on a calculation performed through different counts. Sentiment analysis can be carried out at various levels of reading, considering a whole text or dividing it into parts to understand the sentiment of the various elements (corpus, document, sentences, words). This type of analysis involves several steps: (a) the documents are extracted and normalized (i.e., removal of typos and conversion of upper case to lower case, removal of numbers, spaces, and excess punctuation); (b) the list of positive and negative words is loaded and they are scored; (c) the results are aggregated to get the final output/display. The *syuzhet* package extracts sentiment from texts based on a number of dictionaries, implemented directly in the package, found in *syuzhet* (developed by the Nebraska Literary Lab), *afinn* (developed by Finn Nielsen), *bing* (developed by Minqing Hu and Bing Liu), and *nrc* (developed by Mohammad, Saif, and Turney). The name *syuzhet* comes from the research of Victor Shklovsky and Vladimir Propp, who divided narratives into two elements: the fabula and the plot, also called *syuzhet*. The

syuzhet package has several interesting functions for classifying the feeling of a text. Its vocabularies make it possible to distinguish whether a text is positive or negative and to extract specific emotions. The output of the *get_nrc_sentiment* function shows us how emotions are distributed in our sentences, recognizing 10 types of emotional expressions: anger, anticipation, disgust, fear, joy, sadness, surprise, trust, negative, positive. The *get_sentiment* function provides a total score for each sentence, calculated from the chosen vocabulary. The text can be broken down into sentences using the *get_sentences* function or into tokens using the *get_tokens* function. It is also possible to create a representation of a single text (this function does not apply to unrelated sentences) to observe how sentiment changes within it, using the *get_sentiment* and *get_transformed_values* functions.

Results

The first analysis of the text showed a general overview of the experience of the parenting pairs. During the analytical reading of the text, the researcher identified the relevant meanings expressed by the participants during the interviews and, through a process of comparison and identification of similarities and dissimilarities, converted them into key words or a summary expression, called a “code.” Then, through the identification of groups of codes with similar meaning, the researcher derived conceptual statements called “categories.” This process led to a more abstract and complex

theoretical framework related to a specific topic. Through this inductive-abductive approach, the text of the four interviews was gradually coded into 37 initial codes, which were then aggregated into 5 categories. Each content code associated with the different categories is represented in **Table 1**. According to the results, the categories “ASD” and “Parenting” play a major role over the categories “Family,” “Couple,” and “Social and Public Space,” revealing that parents' lives seem to revolve almost entirely around the child and his or her disorder. Parents organize daily life according to the needs of the child, reducing time for emotional relationships, hobbies and passions. In fact, the codes “Time for self/hobbies,” “Self-image,” and “Work” emerged in the “Parenting” category in a negative perception due to the tendency of parents, especially mothers, to give up self-care and work. Specifically, our results show that mothers tend to devote themselves completely to their children as full-time work (as evidenced by the presence of “work” in both “ASD” and “Parenting” categories), while fathers tend to devote themselves more to work and hobbies. Parenting is thus perceived to be only around child care, and free time is limited and spent primarily in associations and hospitals specializing in ASD and then in occasional relationships with relatives, as shown by the “Dependence/Role Idealization,” “Hyper-responsibility,” and “Abnegation and Absent Presence” codes. Most play/recreational time takes place in the home or in associations dedicated to ASD between the children and their

mother, while very few are spent outdoors and with both parents and children. Parents' poor participation in the social context seems to depend on the child's difficulty in managing in public spaces. The study reveals that parents feel unable to understand their child's attitudes, behaviors, and moods, as revealed by the category “ASD,” particularly in “Inability to decode,” “Perception of autism,” “Perception of emotional state,” “Perception of socialization,” and “Locus of control.” Regarding the type of language used, there is a non-acceptance or an attempt to hide the disorder from oneself. In fact, the “Language Labels” code shows how parents rarely utter the word “autism,” referring to it more often as “the problem.” The html file generated by RQDA-converted to pdf and divided into two parts-illustrates the entire coding process. The first part contains a list of all the initial codes processed. The second part includes the textual passages in an ordered and systematic form corresponding to each code. Through thematic analysis, the 25 most common terms by parent pair and gender were identified. **Figure 1** shows the results of the thematic analysis conducted on the interviews. Among the most commonly used terms common to all interviews, the word “time” stands out, as also shown by the following related words: beginning, always, often, never, now, sometimes, years, afternoon and day. The second is related to actions and includes: saying, taking, giving, doing, playing, going, staying, happening. Regarding the differences in the two pairs, in one it is the mother who is more focused on caring for the child, while in the other

it is the father who takes on this role, as described by the frequency of terms used for the organization of daily life, timing, household management, and expressions related to the child. For more information on the terms used and to compare differences and/or similarities at the couple and gender level, reference can be made to **Figure 2**, which shows for each parental couple four word clouds consisting of the most frequent terms that emerged during the respective interviews. Interview sentiment was measured by applying the *syuzhet* package functions. **Figure 3** shows the frequency of the 10 emotions recognized by the software (anger, expectation, disgust, fear, joy, sadness, surprise, trust, negative, positive) with respect to parent pairs and gender. The results show a prevalence of positive terms. In the case of woman 1, negative emotions follow positive ones, while emotions of trust and expectation, followed by joy, sadness, fear, anger, surprise and disgust, have a lower frequency. In the case of woman 2, positive emotions are followed by trust, which has a slightly higher frequency than negative emotions followed, in this case, by anticipation, joy, sadness, anger, fear, disgust, and surprise. In the case of man 1, positive emotions are followed by negative emotions and trust, which have the same frequency; then, with a slightly lower frequency, we find anticipation followed by joy, fear, surprise, sadness, anger and disgust. In the case of man 2, positive emotions are followed by trust and negative emotions by anticipation, fear, joy, sadness, anger, surprise, and disgust. Comparison by parental couple

shows, in the case of couple 1, greater use of the 10 emotions by the woman, while in the case of couple 2 the situation is opposite. Finally, in terms of the frequency of emotions, greater similarity was reported between woman 1 and man 2. The results are depicted in Figure 3.

Discussion

The main purpose of this study was to investigate, through a qualitative analysis, the perceptions of the parental role, ASD, child-parent relationship, and perceived social support of two pairs of parents with children diagnosed with ASD. From the textual analysis conducted on four individual interviews, five categories emerged: “ASD” and “parenting,” “family,” “couple,” and “social and public space,” with the first two categories mentioned more often than the others. These categories revealed how parents' lives are significantly affected by their child's autism spectrum disorder diagnosis, as also evidenced by parents' tendency to focus only on their child's daily needs. In fact, the study shows that as far as parents' social lives are concerned, they mainly relate to organizations and associations dedicated to ASD support, significantly reducing the time they can devote to themselves, their hobbies and social activities, friends, and couple life. The workload associated with caring for a child with ASD seems to weigh more significantly on mothers who give up their work to devote themselves to the child, as confirmed by the negative meaning of the codes “Time for self/hobby,” “Self-image,” and “Work,” and the high presence of the codes

“Dependence/role idealization,” “Hyper-responsibility,” “Abnegation, and Presence/Absence” in the “Parenthood” category. This result is associated with the code “gender stereotypes” in the category “Social and public space” and is correlated with the codes “wife-mother role perception” and “husband-son-father role perception” in the category “Couple”. Our results confirm the findings of recent literature that the diagnosis of ASD affects the parent's life by reducing the time spent on personal and couple activities. As a result, the parent may feel isolated and the couple relationship may become unbalanced (Markodimitraki et al., 2024). The progressive decline in communication and affectivity within the parental couple - which often focuses only on the parental role, ignoring and damaging the couple relationship - is a common risk for families with children with neurodevelopmental disorders, such as those with ASD (Ratri & Ratnasari, 2023). According to the gender perspective, mothers are more affected than fathers by work overload because of the tendency to attribute and internalize the role of caregiver (Reshi & Sudha, 2022). In fact, several researches confirm the designated role for women in mediating between family and physicians (Gilmore-Bykovskiy et al., 2018; Pillemer et al., 2018; Schaffler-Schaden et al., 2021) and their tendency to blame themselves for their children's behavioral and psychological problems (Vadivelan et al., 2020). Being a parent of children with ASD can lead to a sense of inadequacy and frustration because of the

increased supervision and support these children need while growing up (Sabatino et al., 2020; Saladino et al., 2021) and fear of stigma from the social context (Alshaigi et al., 2020). Regarding the terms used by parents, thematic analysis revealed some common words related to the theme of time, perception, desires, intentions, and actions. The theme of “time” and “actions” could be related to parents' investment of time and energy in caring for their child with ASD and giving up time for the couple and themselves, as confirmed by the literature (Markodimitraki et al., 2024). A similar consideration is possible for the theme of “wishes and intentions” that appear totally directed toward planning and organizing the child's daily activities. This could be a defense mechanism aimed at reducing the sense of helplessness and guilt common to parents of children with ASD (Alshaigi et al., 2020). Finally, regarding the issue of “perception,” it seems that parents remain on the cognitive and logical-rational plane, as evidenced by the use of language that tends to negate the emotional and affective component, favoring the sphere of concreteness and actions. Probably this type of language is driven by the same motivations found for the other topics, namely an attempt to decrease the self-blame associated with ASD children's behavioral problems. Analysis of feelings based on the interviews revealed 10 feelings (anger, expectation, disgust, fear, joy, sadness, surprise, trust, negative, positive). The use of the 10 identified emotions emerges more in couple 1 than in the other couples, denoting

greater maturity and emotional awareness. Finally, regarding the process of monitoring parents' emotions within the interviews, it emerges that woman 1 mostly reported a positive feeling for more than half of the interview, and then peaked negatively and concluded with neutral language. Woman 2 starts with a negative sentiment, then reveals a more positive sentiment that persists until the end. Man 1 begins the interview with a positive feeling, followed by a negative feeling and oscillates between these two components concluding with a negative peak. Similarly, man 2 oscillates between positive and negative feelings, but concludes with a positive peak. The data show an oscillatory pattern of parents' emotions, regardless of gender. One possible explanation could be related to the subjectivity of emotions associated with the child's disorder. Obviously, to obtain a broader assessment in this sense, more pairs would need to be recruited. In general, parents' negative emotions seem to be related to internalized stigma and fear of judgment from the social context. In fact, children with ASD tend to transgress social norms, leading parents to experience negative feelings, such as fear, distress, and anger (Saladino et al., 2021). The most common feelings among families with children with disabilities and neurodevelopmental disorders are often characterized by ambivalence both in dealing with the news of the diagnosis and in identifying and constructing their parenting style. In fact, parents are inevitably not emotionally and cognitively prepared to deal with the disorder, as

is also reflected in their language expressions, from which difficulties emerge with respect to recognizing and managing emotions.

Limitations

Our research has some important limitations: first, the limited sample recruited, and second, the collection of only qualitative data, which potentially limits the generalizability of the results. Therefore, it is suggested that future studies on the topic involve a larger sample and also collect quantitative data to reduce interpretive bias and increase the scientific framework of the results.

Future implications

This article may represent a significant contribution in exploring the emotional state of parents and their perceptions of the diagnosis of ASD in order to implement more targeting and efficient interventions to support them in coping with the diagnosis, building the relationship with their children, managing couple relationship, safeguard socialization, work and recreational activities. In light of this, it might be useful for future research and clinical interventions to focus more on parents' self-empowerment, stress reduction, and improvement of their psychosocial well-being. In this sense it would be useful that these studies and interventions are not limited to the parental role, but involved the parent in all aspects of his/her identity, as wife/husband/partner, as worker, as individual with interests, hobbies, friends. This approach would restore the parent's identity as an individual, with a positive impact on parenting style, parent-child relationships, and communication, improving children's well-being.

Based on the data collected, we also emphasize that special attention should be paid to the caregiver role of women, considering the high investment of mothers in caring for children with ASD, which is associated with the gender roles and stereotypes that characterize the maternal figure, as highlighted by our study. These interventions can reduce mothers' self-blame and stigmatization toward the diagnosis of ASD and the resulting difficulties in managing their children's attitudes and behaviors, which often result in their withdrawal from work, social relationships, and self-care.

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Table 1. Description of codes and categories of parental interviews

Code Categories	Codes	Content
ASD	Attempted solution	Implementation of practices in an attempt to solve some problems related to ASD
	Decoding inability	Inability to understand attitudes, behaviors and moods related to ASD
	Disclosure	The child's degree of openness in telling about himself, in telling his experiences or in making his moods known
	Everyday life	Management of the daily routine
	Future	Hopes and plans for the future
	Job	ASD as a full-time job
	Linguistic labels	Terms and expressions used to refer to the ASD
	Locus of control	Perception of the degree of control, direct or external, of ASD-related events
	Maintenance of problem	Implementation of unsuitable practices for attempting to resolve some problems related to ASD
	Organisation of her/his son's activities	Management of the child's extracurricular activities
	Perceptions of autism	Perception of attitudes, behaviors and moods related to ASD
	Perceptions of change	Perception of the degree of change in ASD-related disorders
	Perceptions of socialization	Perception of the degree of interaction / integration with peers related to ASD
	Perceptions of the emotional state	Perception of the child's emotional state in different contexts and circumstances
	Projects	Participation in treatments and therapeutic projects for ASD implemented by public or private subjects
	Prospect in change	Wishes, hopes and goals for changing ASD-related problems
	Reciprocity	Degree of interest and involvement (parent-child) in each other's daily activities
	The problem	Highlighting of the critical issues related to ASD
PARENTHOOD	Abnegation	Spirit of sacrifice, absolute dedication to the good of the child and to one's duties accompanied by the renunciation of one's interests
	Activity	Daily activities carried out with the child
	Attribution of blame	Perception of possible wrong choices made in the educational process
	Decoding inability	Inability to understand and respond adequately to attitudes, behaviors and moods related to ASD
	Dependence/Idealization of role	Idealization of the role connected with paternity and maternity as defined by traditional cultural canons
	Gender stereotyping	Definition and division of parental roles according to traditional cultural canons
	Iper-responsibility	Extreme sense of duty connected with the role of parent
	Job	Conditioning of non-domestic work activities on the basis of commitments linked to the ASD
	Locus of control	Perception of the degree of control, direct or external, of ASD-related events
	Organisation of her/his son's activities	Management of the child's extracurricular activities
	Parental couple	Degree of agreement in parenting choices related to the educational process
	Perceptions of husband-father role	Perception of the role of husband / father, in a hypothetical and real sense, by the wife
	Perceptions of parent role	Perception of the role of parent, in a hypothetical and real sense, by the spouses
	Perceptions of wife-mother role	Perception of the role of wife / mother, in a hypothetical and real sense, by the husband
	Presence/Absence	How parents live their moments of absence from home and / or the moments of absence of the child
	Self-image	The subject's perception of himself and the image of the person he would like to be
	Time for yourself/Hobbies	Time that parents reserve for themselves and to cultivate their interests
FAMILY	Activity	Daily activities that involve the whole family
	Everyday life	Family organization of daily life
	Presence/Absence	How the moments of presence / absence of the child or parents are managed
	Reciprocity	Degree of interest and involvement (parent-child) in each other's daily activities
COUPLE	Relationship with relatives	Interaction and moments of sharing with the extended family
	Couple's relationship	Moments reserved for the intimacy of the couple relationship
	Parental couple	Degree of agreement in the choices related to the educational process
	Perceptions of husband-father role	Perception of the role of husband / father, in a hypothetical and real sense, by the wife
	Perceptions of parent role	Perception of the role of parent, in a hypothetical and real sense, by the spouses
SOCIAL AND PUBLIC SPACE	Perceptions of wife-mother role	Perception of the role of wife / mother, in a hypothetical and real sense, by the husband
	Associations	Relationship with associations present in the area for the management of disorders related to ASD
	Gender stereotyping	Gender definition and differentiation based on traditional cultural models
	Hospital	Relationship with hospitals in the area for the management of disorders related to ASD
	Perceptions of socialization	Perception of the degree of interaction / integration with peers related to ASD
	Projects	Participation in treatments and therapeutic projects for ASD implemented by public or private subjects
	School	Relationship of parents and children with educational institutions
	Social desirability	Tendency to pursue an image of normality understood as adaptation to the most shared norms within a society

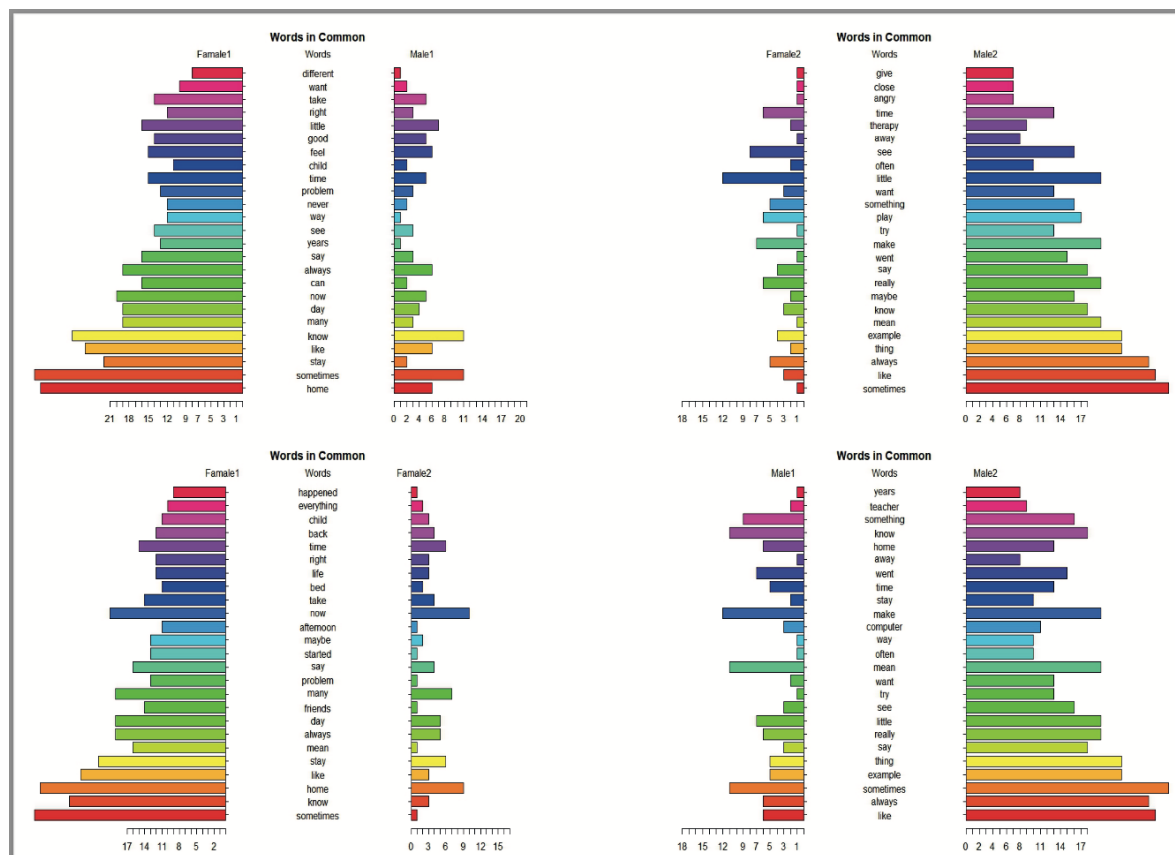
Figure 1. Topic analysis: The 25 most common terms by parental couple and gender

Figure 2. Text Mining: Words clouds compared per parental couple and gender

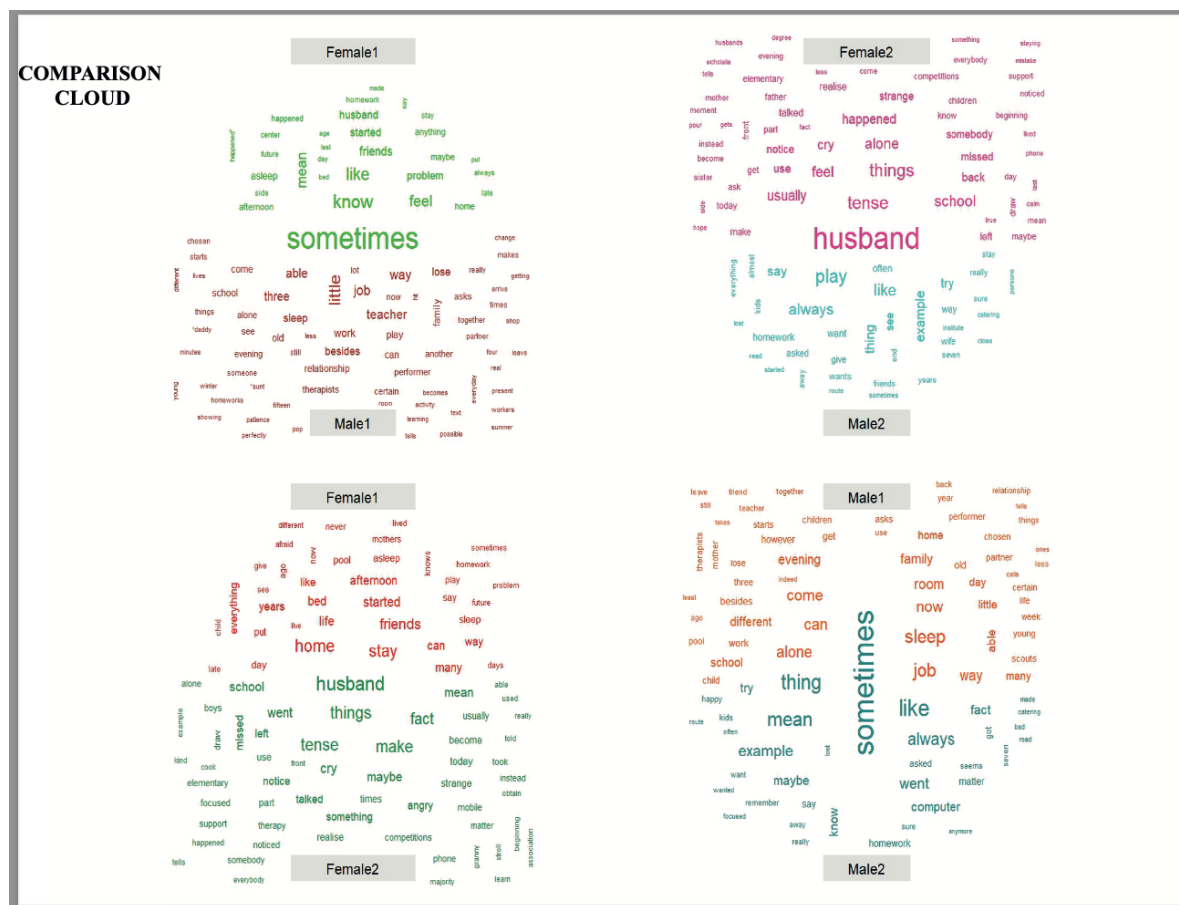


Figure 3. Sentiment Analysis: Frequency of 10 emotions (recognized by syuzhet package) compared per parental couple and gender

