



Sensemaking Process of Parents of Children with Autism Spectrum Disorder: Identification of Specific Clusters of “Sense of Grip”

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Abstract

Autism spectrum disorder (ASD) represents a pervasive neurodevelopmental disorder characterized by persistent atypicalities in social communication and social interactions across different domains of life, often with restricted, repetitive, stereotyped patterns of behaviors, interests, and activities. A large corpus of previous research shows that parental involvement in caregiving is perceived as stressful and challenging, in many cases resulting in poorer parental quality of life. The authors present a quali-quantitative mixed method research on sensemaking process of 34 parents (16 mothers and 18 fathers) of children with ASD. The interviews were collected and analyzed according to the “Sense of Grip” (SoG) methodology. SoG indeed refers to the sensemaking processes that a person realizes to manage the relationship with diseases or disorders by organizing several degrees of flexibility, differentiation, and adaptation to the variability of experiences and contexts of life. This construct of health psychology—semiotically and clinically oriented—is based on specific narrative functions (i.e., temporal, integrative, emotional, sharing, and agentive functions). The cluster analysis procedure allowed to identify three different *SoG profiles*: (a) *enterprising* (parents who are able to construct flexible and dynamic familiar routines), (b) *opposing* (parents who experience the ASD disorder as a deep unacceptable crisis, hindering the rest of familiar and professional activities), and (c) *condescending* (parents who organize family life completely on adherence to medical prescriptions and care protocols). These profiles show interesting implications for clinical practice and support as showing specific aspects of treating, managing, and sharing children conditions within family and relational contexts of life.

Keywords Sense of Grip · Autism · Sensemaking process · Parental care · Clinical health psychology

Introduction

Autism spectrum disorder (ASD) is a pervasive neurodevelopmental disorder. It is characterized by a series of persistent atypicalities in communication and social interactions. ASD resents patterns of behavior, interests, or activities that are rather narrow, repetitive, and stereotyped (APA, 2013). ASD represents a broad category, with a great symptomatological variability that can differ from less serious levels to very serious and maladaptive levels. Many individuals with ASD require ongoing assistance in daily living. Usually, this assistance is provided by the family and especially by the parents.

ASD characteristics (e.g., certain problematic behaviors, relational difficulties, inability to regulate expressions and intensity of emotions, impaired communication skills, sleep problems—see Militerni et al., 2002; Shaw et al., 2022; Volkmar & Pauls, 2003) can influence the entire family system (in particular the parents and other siblings) (Corsano et al., 2017; Guidotti et al., 2021; Pozo et al., 2014) and require a surplus of constant attention with the consequence of periods of stress and with a negative impact on family routines, quality of life (Fante et al., 2024a, b; Musetti et al., 2021, 2024) and on the relationships of the entire family system and its life contexts (school, work, leisure, friends, etc.) (Hayes & Watson, 2013).

It often happens that the condition of the child affected by ASD and the interventions (therapeutic assistance, psychoeducation, speech therapy, etc.) that they need become the only salient elements, while the centrality of parental involvement and their absolute relevance in all of their children's activities is neglected (Davis & Carter, 2008). In fact, parents are in the majority of cases involved in all their children's activities, from the more complex ones implementation of therapeutic interventions to participation in parent training courses, from the effort to create and maintain functional forms of family routine and daily activities to the presence in accompanying and attending all possible relational moments of the children (school, trips, sports, parties with friends, moments of leisure, etc.). Obviously, the assistance provided by specialized centers (both public and private) and highly qualified professional figures is very important and it has been seen as a valid support by parents; however, it is essential that the parents themselves develop strategies, resources, and ways of caring for their child and management of family dynamics by finding personal and functional ways of guaranteeing a balance between maintaining routine forms (tested and reassuring) and processes of development and growth for all members of the family system.

It is necessary to realize that the development in parents of the ability to manage and care for their children with ASD is not exclusively linked to processes of medical literacy, learning of functional guidelines, and implementation of behavioral protocols, which are very often at the center of parenting processes training (Factor et al., 2019; Stasolla et al., 2017). Parental vicissitudes and experiences in such circumstances are very complex, ambivalent, and fluctuating. The parents experience goes through moments of despondency and discouragement, confusion and turmoil due to the traumatic impact of receiving the diagnosis, loss of confidence in their own parental abilities, uncertainty and mourning (due to the loss of the idealized child and the difficulty of imagining future scenarios and adult life of children), feelings of excessive responsibility and stressful overload, feelings of renunciation and loss of one's personal life, feelings of shame in social contexts (e.g., during intense and unmanageable behavioral crises of children) and of loneliness (believing that they cannot be understood by others, that they have remained alone and abandoned by previous networks of relationships and friends) (Lickenbrock et al., 2011). However, the

parents themselves most often show absolute self-denial, energetic determination and tirelessness in assisting and supporting their children and in guaranteeing both participation in the therapeutic paths prescribed by doctors and the structuring of domestic and family habits, but also moments of leisure and recreational experiences (Mello et al., 2019).

Therefore, it is essential to understand the various ways and processes through which parents make sense of these experiences, how they attribute value and meaning, how they are able to adjust daily routines according to medical needs, the growth needs of the child but also the psychological, social and emotional well-being of the whole family. We believe that a narrative-founded research methodological approach is fundamental and useful in order to explore this dimension of the parenting experience (Carpinelli & Watzlawik, 2023).

The narrative process of the sense of the experience of illness is essential for understanding the psychological, emotional, and relational adaptation to the specific medical conditions of one's children. Storytelling is considered a mode of psychic functioning which, through the configuration of stories, allows the creation of temporal, spatial, relational, and agency links between the elements of the experience, its participants, and the discontinuities that intervene (De Luca Picione et al., 2018; De Luca Picione & Valsiner, 2017; Freda, 2008; Freda et al., 2023; Smorti, 2020). The narrative process performs an interpretative function ensuring the recovery of a continuity of meaning in the face of turning points, existential ruptures, crises, and discontinuities; however, it also acts in a constructive and creative direction by providing fictional aspects that help to imagine possible future scenarios who broaden one's own emotional, reflective, agency, and relational repertoires.

Narration as a process of intrapersonal and interpersonal symbolization fulfills the fundamental human need to experience a feeling of identity and continuity over time by building stories, values and meanings, within intersubjective, historical, and cultural environments (Bruner, 1990; Chaudhary et al., 2017; De Luca Picione & Valsiner, 2017; De Luca Picione et al., 2018, 2019a, b; Freda, 2008; Tateo, 2023; Thorton, 2010). However, narration also becomes a fundamental driver of transformation and growth when it is not simply aimed at the mere description of one's own experience, at maintaining a definite stability, but becomes an opportunity to negotiate the meaning of experience especially in conditions of uncertainty and crisis (Bruner, 1990; De Luca Picione, 2021; De Luca Picione & Lozzi, 2021; Marsico, 2012, 2018; Moscovici & Marková, 1998; Murray, 2002).

When a parent is confronted with a child's illness/disorder, they activate narrative processes of reconstruction of their own identity, of redefinition of their own goals and relationships, of re-modulation of their own activities and habits in the contexts of belonging. Through the narrative process, a mother or a father are engaged not only in recovering the meaning of their parental experience, whose normativity has been disturbed by the medical conditions of the child, but they are also intent on regulating emotions and feelings, redefining intersubjective positionings, reformulating new strategies, actions, and future goals.

In our study, the sensemaking processes of the parental experience with children with ASD are explored and analyzed in the light of the conceptual perspective of the psychological construct of the parental *Sense of Grip* (SoG) with respect to the conditions of one's own child (De Luca Picione et al., 2022; Freda et al., 2019; Maiello et al., 2022b; Savarèse et al., 2020). This clinical and research construct was originally developed in pediatric healthcare contexts where parents were struggling with their children's chronic diseases (for example, diabetes, hereditary angioedema, rheumatoid arthrosis) and it made possible to explore the different configurations of meaning that oriented parental actions, choices, and relationships.

Although there are notable differences between situations in which parents deal with their children's chronically ill health conditions (over time they are able to understand their

situation, they ask questions and they gain more and more autonomy in managing their own health) and neurodevelopmental disorders of the autism spectrum (where very often it is not possible to understand the individual with this diagnosis and there is an impairment of communication, behavior, and social relationships); in any case, these are conditions that are not resolvable over time and which require intense processes of elaboration, processes of sensemaking of experience, and processes of imagination to make possible future transformation and adaptation.

Therefore, we believe that it is very interesting and useful to use the clinical construct of SoG for the first time in the context of ASD by investigating the sensemaking processes of parents with children with ASD.

The present study—conducted according to a mixed-method process—integrates the narrative analysis of the textual corpus of the interview and a cluster analysis with the intention of finding typical and widespread sensemaking configurations of the way parents deal with the disorder of ASD. The aim is therefore to identify specific knowledge, psychological and relational needs in the light of which to plan psychological-clinical interventions in support of parenthood and the entire family.

Purposes of the Research

The objective of this research consists in the exploration of the narrative corpus of the experience of parents with children affected by ASD and in the identification of specific profiles of Sense of Grip intended as configurations of sense, elaboration, and management of the conditions of one's own children and of the whole family.

The Parental Sense of Grip

In this and next paragraphs, we present the construct of Sense of Grip (SoG) and its conceptual and methodological stances. Since it represents the architrave of our research, we intend to offer elements for understanding its origin, rationale and usefulness.

Starting from a clinical, semiotic, and dynamic perspective of the processes of sensemaking of one's own experience, we have developed the *Sense of Grip (SoG)* model (Freda et al., 2019). This model intends to underline the role of sensemaking processes (De Luca Picione, 2020; Neuman, 2014; Salvatore 2015; Salvatore & Freda, 2011; Valsiner, 2007) in the elaboration of the diagnosis and in the development of skills useful for the management of disease and ailments, and the promotion of health and well-being.

By the term “*SENSE*,” we intend to underline the central role that the sensemaking processes assume in orienting the adaptation of the individual to the disease from a psychological, social, and agentic point of view. The term “*GRIP*” instead refers to the ability to adaption to the mutability of subjective, relational, and environmental conditions, so as to be able to assume the most effective positioning possible in order to maintain good management and a good experience of coexistence with children and the specificity of their disorder. An example extracted from the sport context may be useful to express the idea of *Grip* to which we are referring: the tennis player's grip on their racket must be able to assume a position suited to her own physical characteristics, to grasp the variations in the ball trajectory from environmental variations, to orient the racket in the most suitable way to intercept ball. If you observe the dynamics of the tennis player's movements, you will notice the pose of the athletes which is anything but static, sometimes twisted, constantly looking for the best position to receive the blow.

Just like a sportsman, each parent grappling with the care and management of a child with a disorder is immersed in a certain environment and brings into play different resources, skills, and potentialities. On the one hand, the parent is confronted with the general characteristics of the specific disorder and with the indications and information that come from the healthcare and welfare field. On the other hand, however, the parent is confronted with the specific conditions of their own life, of their own child, and of their own family. The Sense of Grip is precisely the changing and dynamic result of this ongoing renegotiation between the general and singular aspects of one's experience (De Luca Picione et al., 2019b; De Luca Picione, 2015, 2020).

The SoG construct includes both the transversal and general elements related to the specific disorder and the peculiarities that subjectively characterize the experience of living with the disorder, which translate into different degrees of flexibility and adaptation. The condition of suffering a disorder is not equivalent to a static condition; therefore, there is no linear path of development of the SoG: the course of the experience of the disorder over time is not homogeneous, stable. It is inevitable that it intertwines with the processes of transformation of the person, of the family, and with their sense of belonging and social interaction.

Within the perspective of Clinical Psychology of Health and Semiotic-Cultural-Dynamic Psychology in which we move, the reference to the Sense of Grip can be useful for the planning of support and psychological interventions to favor the development of parents' sensemaking processes and their ability to manage disorders of their own children.

In recent studies (De Luca Picione et al., 2022; Freda et al., 2015, 2019; Maiello et al., 2022a, b), we have focused on pediatric and healthcare contexts, developing a research model and intervention on the sense of parental grip of their children's illness through the implementation of an ad hoc semi-structured narrative interview and a coding system of the inherent narrative corpus. Besides allowing a specific clinical focus on single stories, this methodology also allows to explore specific semiotic configurations that recur with a certain regularity.

Sensemaking and Narrative Functions in Healthcare Contexts

The construct of the Sense of Grip (SoG) is based on the centrality of sensemaking processes, understood as semiotic processes aimed at promoting activities of construction, regulation, and development of experience within relational contexts (De Luca Picione et al., 2018; Marsico & Varzi, 2016; Salvatore, 2015; Valsiner, 2007; Zittoun, 2021). Within this theoretical framework, a clinical narrative interview was developed and refined (De Luca Picione et al., 2022; Freda et al., 2015, 2019; Maiello et al., 2022a, b) aimed at understanding the way in which the processes of narrative connection organize the development over time of the parental experience of living with the disorder of the children, the understanding of coping methods and the construction of social support.

In particular, sensemaking processes are analyzed with reference to *five narrative functions* that we consider the main trajectories of the sensemaking process in the healthcare field.

Within the framework of the SoG, five main narrative functions are highlighted through which the process of constructing the sense of experience is organized:

1. *Function of temporal organization of the narration (temporal articulation)*. This function allows us to refer to the process of narrative connection of parenting experience with

respect to the specific disorder of the children within a time frame (Brockmeier, 2000). The temporal organization allows events to be articulated in a sequential structure, to distinguish a before and an after, to recognize an evolution, to identify significant turning points. Within this function, we analyze the quality of the process of organizing and differentiating experience phases that underpins different qualities of the experience elaboration process.

2. *Function of interpretation/integration of the disease in one's own life narration.* This function allows us to identify the process by which the narration constitutes the personal theory of the experience of illness on the basis of norms, values, and subjective references (Bruner, 1990; Thornton, 2010). Within this function, we analyze the process of integrating parental experience with respect to the specific disorder of the children in one's own life narrative. It is a process that is concerned with the degree of integration of the "canonical," according to which the disorder can assume the meaning of just one of the multiple aspects that form one's own story; or, conversely, the disorder appears to be an experience that remains unhooked, isolated, alien or even "enemy," as it is signified as a threat to an ideal canon (Bruner, 1990; Thornton, 2010).
3. *Function of narrative articulation of emotional experience (emotional regulation).* This function refers to narration as a dynamic semiotic process capable of regulating the relationship between affects and meanings (Salvatore et al., 2022; Salvatore & Freda, 2011; Tossici & De Luca Picione, 2024). Within this function, we aim to observe: (A) the presence of processes of denomination and differentiation of the emotions and feelings (observing different qualities and processes of emotional experiences). (B) The modalities of articulation of the emotional experience in a narrative that contemplates variegated and/or ambivalent aspects. (C) The wealth of narrative passages is dedicated to the description of emotional experience and their implications (Salvatore et al., 2022; Tronick & Beeghly, 2011; Valsiner & De Luca Picione, 2017).
4. *Experience of Sharing Function (Social Support).* With this function, we refer to the organization of connections between the self and the world, and between oneself and the others. In fact, narration works as a device for sharing with others, organizing and re-organizing relationship plans in its various aspects and roles (Rimè, 2009). Through this function, we analyze the ways in which it is possible to tell the experience of illness to other people and the meaning attributed to this dialogical process.
5. *Agentive function.* With this function, we intend to indicate the way of constructing the links between the story of the experience and one's own personal strategies of decision making. This function has to do with the construction of an active and pragmatic competence in the use of information as meaningful resources useful for making decisions regarding the conditions of one's own children, evaluating their impact on daily management and on possible changes due to one's own life scenarios. The narration is configured here as an open and dynamic process of action orientation (De Luca Picione et al., 2017, 2018, 2019b).

Participants

This study is a part of a broader research project on the QoL of parents of children and adolescents with ASD (Fante et al., 2024a, b; Musetti et al., 2024). The study was conducted in Northern Italy at two ASD treatment centers. Sample is composed by parents of children with ASD diagnosis. A total of 34 participants (16 mothers and 18 fathers) involved in for the present study (mean_{AGE} = 42.68 ± 5.056; 52.9% female).

The inclusion criteria of participants were as follows:

- (a) Being a parent of child whose formal ASD diagnosis was made at least two years prior to the data collection;
- (b) Each participant's child must be between the ages of five and eleven and have a Level 2 or 3 severity. According to the American Psychiatric Association's (2013); DSM 5 criteria for ASD, these severity levels correspond to the following: Level 2 denotes substantial support needs, marked social communication difficulties, and restricted, repetitive behaviors; Level 3 denotes severe support needs, critical social communication impairments, and repetitive behaviors that significantly impair daily functioning;
- (c) The child was receiving multidisciplinary intervention for ASD, wherein parents of children with ASD collaborate with clinical psychologists, pediatricians, child neuropsychiatrists, and/or speech pathologist to deliver treatments;
- (d) No other family member has a chronic health condition or disability;
- (e) Participants had to be able to understand Italian Language

Demographic characteristics disaggregated for parents' roles are reported in Table 1.

Methodology

A mixed-method research design was carried out which includes the following:

- (a) A qualitative component aimed at the collection and the analysis of the semi-structured narrative interview on the Sense of Mastery of Parents with children affected by ASD;
- (b) A quantitative component aimed at obtaining clusters of specific Sense of Grip.

Interviews lasted in average 1 h and 15 min (the shortest one lasted 43 min, the longest one lasted around 2 h and 10 min) and were conducted in a private place where others could not overhear; the interviews were audio-recorded and then transcribed *verbatim*.

Table 1 Participants' demographic characteristics

Variable		Parents' role (%)		X^2	<i>p</i>
		Father	Mother		
Educational level	<i>Elementary school</i>	0 (0.0)	0 (0.0)	5.045	.169
	<i>Middle school</i>	2 (5.9)	0 (0.0)		
	<i>High school</i>	10 (29.4)	8 (23.5)		
	<i>Bachelor's degree</i>	4 (11.8)	9 (26.5)		
	<i>Postgraduate training</i>	0 (0.0)	1 (2.9)		
Occupational status	<i>Unemployed</i>	0 (0.0)	2 (5.9)	7.997	.046
	<i>Unoccupied</i>	0 (0.0)	5 (14.7)		
	<i>Employee</i>	14 (41.2)	9 (26.5)		
	<i>Freelance</i>	2 (5.9)	2 (5.9)		
Social status	<i>Married/Cohabitant</i>	14 (41.2)	16 (47.1)	.016	.900
	<i>Divorced/Separated</i>	2 (5.9)	2 (5.9)		

Subsequently the interviews were analyzed according to a specific semiotic-narrative coding grid. Both the interview and the coding grid have been verified and implemented previously in research for the analysis of interviews with parents in other healthcare contexts (De Luca Picione et al., 2022; Freda et al., 2015, 2019; Maiello et al., 2022a, b). Once all the interviews have been analyzed and codified, a cluster analysis was carried out which brought out a series of clusters. They have been interpreted as parental Sense of Grip Profiles and provide insights into specific multimodal configurations of recurrent sensemaking processes of parenting experience with children with ASD. These clusters were also correlated with an external measure of parental self-efficacy detected through a questionnaire.

Synthetically, two steps for data collection had been carried out:

(A) SoG Semi-Structured Interview was administrated.

(B) The *Child Adjustment and Parent Efficacy Scale-Developmental Disability* (CAPES-DD) questionnaire was administered. Italian adapted version of the scale was used (Benedetto et al., 2021). It is a self-report scale adopted for assessing emotional and behavioral problems of children with developmental disabilities as well as caregivers' self-efficacy in managing these problems. It is composed by 24 items and each item is rated on 4-point Likert scale (from 0 = "not true of my child at all" to 3 = "true of my child very much, or most of the time"). CAPES-DD presents subscales regarding (1) *behavioral problems* (item example: "loses their temper," "hurts me or others (e.g., hits, bites, scratches, pinches, pushes)," "Breaks or destroys things"); (2) *emotional problems* (item example: "seems fearful and scared," "cries easily for no apparent reason," "seems unhappy or sad"); (3) *prosocial behavior* (item example: "cooperates with self-care routines (e.g., getting dressed)," "gets along with adults," "shares with others"). Furthermore, the first 16 items are adopted to assess parents' self-efficacy on a 10-points scale. Higher scores indicate greater levels of child behavioral or emotional problems, as well as higher score on self-efficacy. For the present study, internal consistency of CAPES-DD was measured (behavioral problems $\alpha_{\text{Cronbach}} = .80$; emotional problems $\alpha_{\text{Cronbach}} = .67$; prosocial behaviors $\alpha_{\text{Cronbach}} = .65$; self-efficacy scale $\alpha_{\text{Cronbach}} = .88$).

Finally, a list of items was added to collect demographics characteristics of parents (i.e., educational level, occupational status, social status).

- *Adaptation of the Sense of Grip interview for parents with children with ASD disorders.*

The narratives were collected through the administration of the semi-structured interview on the SoG (Freda et al., 2019; Savarese et al., 2020; Maiello et al., 2022b). This semi-structured interview was built by adapting the previous pediatric versions of the *Interview on the Sense of Grip of parents managing children's chronic illness* (Freda et al., 2019; Savarese et al., 2020; Maiello et al., 2022b; De Luca Picione et al., 2015; Barone et al., 2019). This interview is made up of 15 open questions aimed at exploring three main domains of the experience of illness:

1. The interpretation of the disease;
2. The processes of dialog in the family and with the social context;
3. The coping and managing of the disease in daily life.

The aims that we intend to pursue through the interview questions is to stimulate the parent, in recounting their own experience, to cross different narrative registers. Some questions therefore aim to solicit the exploration of the processes of narrative construction of the sense of experience, activating processes of semantic memory; other questions focus on narrating events by eliciting episodic memory, and finally a question elicits the production of a counterfactual narrative.

Adaptation of the clinical interview on the parental Sense of Grip in ASD context

- 1 *When and how did you discover that your child suffers from ASD/?*
 - 2 *When did you realize that she/he was suffering from ASD? How did you feel?*
 - 3 *How has your family's life changed after your child's autism diagnosis? (And for you in particular?)*
 - 4 *What are the main difficulties you had to manage?*
 - 5 *What aspects of your child's disorder have had the greatest impact on your quality of life (impact on physical, economic-material, social and emotional well-being)?*
 - 6 *Tell me about a salient symptomatic episode/the most significant and recent episode for you (within the last six months or, if there hasn't been one, within the last year)*
 - 7 *In this situation, in your opinion things would have gone differently if . . .*
 - 8 *What do you do to take care of ASD in your daily life?*
 - 9 *In there something or someone that you consider as a support in dealing with the disease?*
 - 10 *How do you talk about ASD in your family, at work or with your friends? Which words do you use to define it?*
 - 11 *Has the way you speak of ASD changed over the years?*
 - 12 *In your experience, how should interventions to improve the quality of life of parents be designed (ways, contents, organization, etc.)?*
 - 13 *What would you say to a parent who is dealing with a diagnosis of autism in their child? What advice from your experience would be helpful?*
 - 14 *How do you imagine your life in 10 years?*
 - 15 *Would you like to add anything that we haven't asked you?*
-

Analysis and Coding Procedures of the Narrative Interview

After the verbatim transcription of all the narrative interviews, we proceeded to the analysis and coding of the entire narrative corpus, which was carried out by five independent researchers, trained to administer and analyze the interview according to the specific grid. In cases where there was a discrepancy in the coding, we proceeded with a group discussion until we always reached an agreement between the researchers. The results of the qualitative coding were transposed into a codebook and transformed into categorical variables.

The interviews were analyzed through a *theory-driven approach* (Salvatore, 2015) starting from a narrative perspective that provides for a semiotic and functional analysis of the narratives (Freda et al., 2019; Jacobi & Macleod, 2011; Savarese et al., 2020; Schiff, 2017). This analysis of the sensemaking process is carried out on the narrative text by identifying the specific modalities of the 5 narrative functions described in the SoG model: *temporal articulation, interpretation/integration of the disease, emotion regulation, social support, and agentive function*, as described above (Freda et al., 2019).

The analysis of these narrative functions is carried out by identifying the specific ways in which each function is instantiated within the narrative text. This grid is the result

obtained from the application of this methodology in a series of previous research (De Luca Picione et al., 2022) (Table 2).

Below, we present in detail the methods identified for each narrative function, reporting as examples some narrative excerpts from the interviews:

- Temporal Articulation Function (A)

For this function, three main modalities have been identified which allow us to grasp the most relevant articulations of this process:

A1. *Absence*. The lack of a process of dynamic articulation in the narration of the parents' experience is noted. It is as if the moment of diagnosis were not recorded as a critical event that carries within it a potential discontinuity and the narrative was not articulated in a "before" and an "after," nor it is able to express a dynamism due to the passage of time.

An example from the corpus: "*Life is always the same. The birth of our son X changed nothing. I continued to work and run the family business as if nothing had happened... trying to pretend that everything is always the same.*"

A2. *Block*. Time appears as trapped, frozen at the moment of receiving the diagnosis. The narration expresses the same level of interruption of the narrative continuity experienced at the moment of receiving the diagnosis despite the passage of time.

An example from the corpus: "*I don't want to think about it because I don't see beautiful things. Because the child is always expected to grow up and take the path of him ... I am disheartened because I think that ... I will always have to take care of my child. I see myself a bit trapped in this... and I wonder if I'll have the strength to continue, because I'm 42 now... but we're getting older... I don't know... I don't know how he will be, I don't know how we're going to do it. I see it very badly... I'm very pessimistic... if I look at the future. I don't want to look there yet. I try to do it day by day. I do not know.*"

Table 2 The semiotic-narrative coding grid of the interviews

Narrative Function	Modalities	Codebook
Organization of temporality	<i>Absence</i>	A_1
	<i>Crystalization</i>	A_2
	<i>Transformation</i>	A_3
Interpretation/Integration of disorder	<i>Conflict</i>	B_1
	<i>Tolerance/resignation</i>	B_2
	<i>Coexistence</i>	B_3
Regulation of emotions	<i>Vagueness</i>	C_1
	<i>Discretization</i>	C_2
	<i>Differentiation</i>	C_3
Social sharing	<i>Loneliness</i>	D_1
	<i>Interchange</i>	D_2
	<i>Sharing</i>	D_3
Agentivity/Orientation to action	<i>Limiting</i>	E_1
	<i>Executive</i>	E_2
	<i>Flexible</i>	E_3

A3. *Transformation*. The narration takes account of temporal articulation processes, of a series of narrative transformations of the relationship with the health conditions. Time is the catalyst for new meanings to be achieved and/or reworked.

An example from the corpus: “*My wife and I initially suffered a shock. We couldn’t believe it, we didn’t have the courage to tell our grandparents. Then over time we managed to offer X everything he needed and now I am convinced that his arrival has taught each member of the family a lot....*”

- Integration Function (B)

The following modalities have been identified for this function:

B1. *Conflict*. The narrative does not integrate elements of the experience of illness into a self-narrative that is causally and organizationally coherent and coherent. The aspects of child’s condition appear unacceptable and always in friction with all other activities or experiences.

Some examples from the corpus:

“*I got angry with myself, also because I ended up working in a factory and I didn’t finish studying... X’s birth and his disturbance meant giving up many things for me....*”

“*Certainly for me, as a mother, having a son like X has limited me a lot in being able to do things, perhaps for myself. ... I have less time available, so since he was born I have almost never been able to play sports and find space for myself. That is, even now if I have to think about the typical week, I never have my own space. That is, if I consider seven days a week, there isn’t a single moment for me.*”

“*Our dream... I had to go back to my country of origin, I had to create a life there... that is, then you realize that therapy begins, the first year and the second year and then you understand that your dreams no longer exist, that is, the whole life must be organized according to the needs of the child.*”

B2. *Tolerance–resignation*. The narration assimilates, without there being a transformation, the disease element as a “chronicle,” as a “fact,” without mediating and negotiating the meanings based on one’s own experiences/specificities. The child’s condition is recognized and named, however it appears as an object with which one cannot help but confront and to which to resign oneself.

An example from the corpus: “*Then, the... there were moments of stress, but let’s say that in the last two years my husband and I have also begun to live better. We know that there are many things to do for X. We can’t waste time, they are necessary and we can’t think twice... reality must be accepted and you can’t do anything else but follow your son.*”

B3. *Perspective coexistence*. The narration articulates the element of child’s condition within a broad self-representation oriented towards eudaimonic well-being. The parent recognizes the disorder and can live with it, taking advantage of life experiences, the possibility of integrating resources and limitations connected both to the disease and to one’s own needs/requirements.

An example from the corpus: *“In the beginning it was terrible, we didn’t know how to do it and we didn’t have much experience... each of our actions or choices always seemed like a mistake that implied a series of worsenings... now my husband and I know how to organize ourselves and we manage to find the time so that each of us including our son is able to do everything he likes. My husband likes to fish and often takes our son with him because he is appreciating the calm and peace of the lake... walking in the mountains is very good for me, and I see that X also appreciates this activity....”*

- Articulation Function of Emotional Experience (C)

Below are the three modalities that have been identified for this function:

C1. *Vagueness*. The narrative process uses very generic terms with little emotional connotations, polarized on very intense, generalized and vague dimensions (good/bad, good/evil, pleasant/unpleasant, inside/outside, etc.).

An example from the corpus: *“I’ve never been able to be happy since they threw my son’s diagnosis at me... everything fell into darkness, everything is a pain”*.

C2. *Discretization*. The ability to use a specific emotional lexicon to describe illness experiences is observed. Emotions can be named, even if it is a mainly descriptive level of a very linear type.

An example from the corpus: *“But then I, I personally felt the blow right away. I had 15 days a bit... Even 20 days of bewilderment because you probably blame yourself a little for what happened. But then I reacted quite well, well, there are moments of discouragement and moments of confidence.”*

C3. *Differentiation*. Within these narratives it is possible to grasp the process of naming with reference to specific conditions, contexts and actors of the experiences. The narrative seems capable of expressing the affective nuances, the ambivalences, the co-presence of opposite affective tones, the different gradations and emotional transformations that have occurred over the time of the experience, producing differences, for example, between various contexts, or with respect to the same experience over time, or still articulating emotional nuances rich in affective meaning.

An example from the corpus: *“Since the adventure with our son began we have gone through many difficult moments... at certain moments the sadness seemed pervasive, then my wife became very angry... I was often anxious when we went out and we were around... I slept fitfully at night and day at work I tried to be brave and be optimistic. Slowly we have learned to rejoice in small successes, we are happy when X is invited to a party with friends, we are frightened when the teacher changes at school and we know that a demanding period of re-adaptation will follow....”*

- Function of Social Sharing (D)

Also for this function, three main modalities have been identified:

D1. *Isolation*. The person says they avoid talking about child's conditions. The topic of ASD or related aspects are decidedly kept out of any sharing, it is something that cannot be talked about.

An example from the corpus: *"I try to stay silent... I try never to talk about it... if the other parents talk about their children when they leave school, I walk away... I feel very embarrassed and I think that no one can understand what it means to have a child like this."*

D2. *Information Exchange*. The person uses the narrative of events related to the disease for informational purposes. These storytelling methods appear to be connected to the possibility of transmitting information or requesting it from others. The form appears rather stereotyped, full of forms of common sense. The narration seems to have the function of informing others of one's point of view without highlighting a real openness to the contribution of the other to incorporate and/or integrate the other's meanings.

An example from the corpus: *"I talk about it more or less with all the closest relatives, that is, from my father to brothers-in-law who live next to me... and I also talk about it with friends and colleagues, let's say without particular hesitation or problems, let's say. It is important that they know what it is. I also talk about it at the sports club I frequent, it's a closed, safe, protected place... it can be an opportunity for X... where to stay in the future as well."*

D3. *Discursive negotiation (Sharing)*. The purpose of narrating one's experience is to show one's point of view, transform one's narration into dialogue with the other or contribute to the possibility of transforming the other's point of view through one's own experience. In this dialogic modality, there is an intent to share the meaning attributed to the experience of the disease and to the expertise acquired over time in daily management.

An example from the corpus: *"So there has always been a lot of dialogue anyway, there has always been the possibility of discussion also on a moral level with the others... which is the thing that in the end, apart from all the technical, psychological, etc., about their children... many parents like to be able to exchange a few words with the freedom to be able to confront... not only with the psychologist or the doctor, but also with the girl, the lady who follows X because... yes, one feels a little more understood, here it is."*

- Agentive Function (E)

Three methods are also identified for this last function:

E1. *Limiting*. Narratives are characterized by the presentation of processes of limiting or avoiding activities of daily living, social and recreational activities. Avoidance is the strategy mainly adopted for dealing with the disease in daily life in order to reduce possible risks associated with such activities.

An example from the corpus: *“If we are invited to go out with friends, we say no or one of us stays with the children, often the mother. We don’t do much social life, it’s a big limitation having to continuously follow your child’s requests and needs... The greatest impact is on stress, especially in public, it’s not easy to manage. A defective child is not beautiful... we prefer to do fewer things rather than get nervous or tired further.”*

E2. *Executive*. These are narratives in which the decision-making process is structured on a strong adherence to medical and therapeutic suggestions. Within these narratives, there is no mediation process between them and the subjective baggage of experiences.

An example from the corpus: *“My life is all about things to do... in the morning for my job and in the afternoon all the things my son needs. We are very careful to do what the neuropsychiatrist and the therapist tell us... each of their advice is an order for us. Woe if my husband, or grandparents, don’t follow the instructions.”*

E3. *Flexible*. The agentive function within this modality does not present a single strategy for coping with the experience of child’s ASD management; rather it shows a process of continuous negotiation between personal desires, needs and the indications necessary for the management of the pathology. These narratives appear rich in a flexible and heterogeneous set of strategies, configured according to contexts, needs and resources.

Some examples from the corpus: *“Then, it’s not a matter of accepting or not, that comes spontaneously; perfect there is a problem, we need to address it. That is, it’s not that... so it’s not automatically experienced as a problem.... but then a whole series of... different mental reactions are triggered, that is, in any case you see the person, you see that he has difficulties and you try to understand how to be able to deal with it, how to make everyday life as simple as possible, which in many cases is missing. After a few years we are able to choose different things that are good for the whole family and also for X’s younger sister...”*

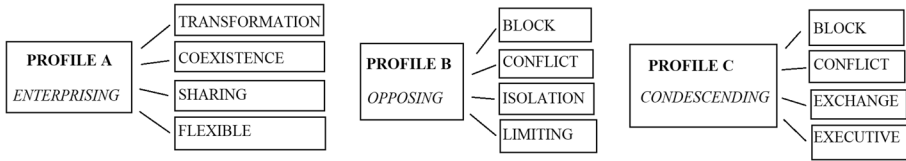
“His biggest difficulty, which is impatience, is linked to aspects of food... we go to the mountains for a week every year in July and when we go to dinner, I go down to the restaurant first, I order the menu and when the food arrives, already at the table, I call Elisa and him to come down, to avoid him waiting at the table, which is something he bears very badly.”

Results

- Profiling of Sense of Grip

The *TwoStep Cluster Analysis* procedure for the categorical data obtained following the coding on the five domains of the functions on the Sense of Grip was performed. The analysis was performed by minimizing the Bayesian Information Criterion (BIC) in order to identify the optimal number of clusters. Each cluster was interpreted as a profile characterized by the most recurring Sense of Grip modalities. Subsequently, a label was attributed that best contributed to explicit the co-presence of the domains of the functions.

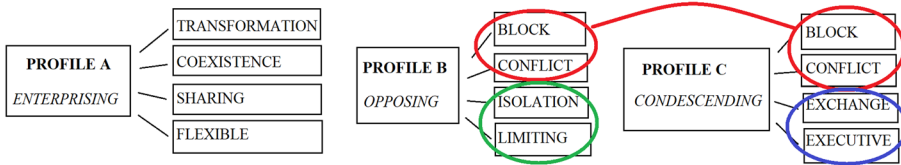
The TwoStep Cluster Analysis generated three clusters, for which the silhouette measure stands at a sufficient level of cohesion and separation (Fair=0,3), which were interpreted and labeled with regard to frequencies of the modalities of SoG functions (Table 3).



- Profile A, defined as *Enterprising*, is mainly described by following specific modalities: “transformation” in the organizational function, “coexistence” in the normative function, “sharing” in the discursive function and finally “flexible” in agentive function.
- Profile B, defined as *Opposing*, is characterized by following specific modalities: “block” in the organizational function, “conflict” in the normative function, “isolating” in discursive function and “limiting” in agentive function.
- Profile C, defined as *Condescending*, is mainly described by following specific modalities: “block” in the organizational function, “conflict” in the normative function, “exchange” in the discursive function and finally “executive” in agentive function.

Table 3 Sense of grip profiles

Function	Domain	Profile (%)			X ²	p
		A	B	C		
Organizational	<i>Absent</i>	0 (0.0)	1 (2.9)	1 (2.9)	1.775	.412
	<i>Block</i>	0 (0.0)	5 (14.7)	4 (11.8)	11.289	.004
	<i>Transformation</i>	14 (38.2)	2 (5.9)	5 (14.7)	9.391	.009
Normative	<i>Conflict</i>	2 (5.9)	6 (17.6)	5 (14.7)	8.760	.013
	<i>Tolerance</i>	5 (14.7)	1 (2.9)	6 (17.6)	3.630	.163
	<i>Coexistence</i>	7 (20.6)	1 (2.9)	0 (0.0)	8.388	.015
Regulatory	<i>Vagueness</i>	8 (23.5)	5 (14.7)	9 (26.5)	2.277	.320
	<i>Discretization</i>	4 (11.8)	3 (8.8)	2 (5.9)	.889	.641
	<i>Differentiation</i>	2 (5.9)	0 (0.0)	0 (0.0)	2.692	.260
Discursive	<i>Isolation</i>	0 (0.0)	7 (20.6)	2 (5.9)	21.097	.000
	<i>Exchange</i>	6 (17.6)	1 (2.9)	9 (26.5)	9.470	.009
	<i>Sharing</i>	8 (23.5)	0 (0.0)	0 (0.0)	13.251	.001
Agentive	<i>Limiting</i>	0 (0.0)	5 (14.7)	0 (0.0)	19.052	.000
	<i>Executive</i>	0 (0.0)	2 (5.9)	10 (29.4)	23.451	.000
	<i>Flexible</i>	15 (44.1)	1 (2.9)	0 (0.0)	30.488	.000



- Profiles' Comparison on Measure of Study

ANOVA shows significant differences between the mean scores of the three profiles for the “emotional problems” subscale of the CAPES-DD ($F_{2,31} = 4.777$; $p < .05$). By applying Bonferroni’s post-hoc test on this variable, profile A (I) results differentiated from Profile C (J) (Difference $I-J = -1.106090$; $p < .05$). In the latter, the level of emotional problems is higher than in profile A (mean score $_{\text{Profile A}} = -4.583.025$; mean score $_{\text{Profile C}} = .6.477.875$). No differences for other measure with regard to profiles were found.

On a purely descriptive level, the majority of “mothers” (66.7%) belong to profile A, the “fathers” to profile C (63.6%); while, in profile B, we find an equal number of fathers and mothers.

Discussions

The three obtained clusters allow us to observe the most recurring configurations of how parents give meaning to experience of caring for their child with ASD and managing the family system. In all cases, it is a matter of balancing efforts between the needs connected to the disorder and the search for familiar daily routines.

In Profile A, *Enterprising*, we observe a series of ways that express the parent’s ability to find *flexible and dynamic forms* of regulation with their own life contexts. We find that an initial difficulty due to ASD has been experienced but also that it has been addressed by seeking ways of personal management within one’s own family system. We also find that this configuration is characterized by *openness* and *sharing* between the family and the world. The disorder does not represent the exclusive element that saturates the history of these families, rather it represents only a part. In fact, parents know how to identify areas of confident and trusting coexistence in which there is room for planning, for the future, and for integrating many other experiences into life for the child with ASD but also for all the other members of the family.

In Profile B, *Opposing*, the advent of the ASD is considered as a moment of rupture that has taken the form of a block from which it is not possible to get out. The dominant sense of this profile is a *conflictual dimension of renunciation*, of loss that marks the parents. They feel deprived of their life to follow the needs of their children. The ASD disorder is considered as an *antagonist*, as an *adverse condition* to the growth and transformation of the individuals in the family. The major emphasis of such conflict is on the *limitation* for their lives. From the point of view of social relationships and the discursive registers used, there is a clear preference for *silence*, for avoiding talking about it with others (relatives, friends, colleagues, etc.).

Profile C, *Condescending*, brings into salience - in the same way as profile B - a dimension of temporal block, a difference between a before and after the diagnosis of ASD, and a conflictual dimension. The conflict however is expressed here not in opposing and privatives terms; rather it is in full compliance with all that is necessary to do for the care and needs of the child. In fact, if from the point of view of the *integrative functions* there is a conflictual dimension, nevertheless from the point of view of the agentive functions we find a *full adherence and compliance* to the medical indications and prescriptions. The family life of these parents is narrated in conflicting terms but not placing the emphasis on everything they have had to give up, but on everything they diligently and regularly do to assist their children and to offer them all the assistance and therapies that have been recommended to them. Also from a social and discursive point of view, the parents of Profile C continuously exchange information (in terms of reception and transmission of informative messages) in a technical way that is purely functional to the execution of the tasks (with doctors, with therapists, with teachers, with instructors, etc.).

It seems interesting that at a descriptive analysis level, mothers belong more to Profile A, *Enterprising*, while fathers instead fall more into Profile C, *Condescending*. As regards Profile B, *Opposing*, we find equally distributed mothers and fathers.

From the ANOVA, it emerges that the only elements of a significant relationship between the clusters and the CAPES-DD scale are to be found in the “emotional problems” subscale. This subscale tells us that parents feel that their children’s emotional problems (e.g., crying, fear, impatience, irritation, sadness) are particularly difficult and complicated to manage. The parents of *Profile C* are those who mostly show this, reducing their perception of self-efficacy, while the parents of Cluster A are those who express the least difficulty with respect to this area of experience and are therefore able to feel they have a good sense of self-efficacy.

Surprisingly, we note that none of the three specific modalities (*vagueness, discretization, and differentiation*) that pertain to the *regulatory function* (inherent in the ability to express, treat, and regulate one’s own emotions and affective states) contributes to defining the three clusters.

If the first profile (Profile A) shows participants who are able to live with their child’s distress, those who belong to the last two profiles show a “static” situation, where in one case there is a mere execution of the tasks that need to be fulfilled for the well-being of the child (Profile C), in the second case (Profile B) the discomfort is experienced as limit with which to constantly deal.

Conclusions

Our study based on the exploration of the sensemaking processes of parents with children with ASD has allowed us to highlight different ways through which they simultaneously manage both the specific conditions of their children and family dynamics and routines. For this study, we referred to the construct of parents’ Sense of Grip, which considers how each parent as an individual that gives value and meaning and implements their own way of dealing with the child’s health conditions, by acquiring specific skills based on the needs, contexts, and life phases. Through a specific semi-structured clinical interview—ad hoc elaborated—to deepen the SoG it was possible to highlight how narrative processes in reference to one’s own parenthood configure a series of ways of constructing the subjective meaning attributed to child’s life, the ways to communicate it and deal with it in everyday life.

Parents with ASD children play a decisive role in the management of all the care practices and procedures of their children, and obviously not only. They often feel overwhelmed by excessive commitments, responsibilities, and chores, and declare great fatigue; however, almost all show total dedication and tell of the effort to balance the needs of their children with those of the whole family. Being able to study and identify these ways represents an essential challenge to guarantee them forms of elaboration, support and enhancement of their capacities. There are relevant implications. As we have already observed in other contexts where parental care is confronted with healthcare processes (De Luca Picione et al., 2015, 2019b, 2022), we consider that the parental Sens of Grip is not a skill that it can be implemented through standardized protocols or purely educational interventions. Its promotion and development are possible first starting from the recognition of the specific forms of sensemaking it assumes in daily life, in relationships with others, in the management of routines, choices and established practices. For these reasons, the narrative frame is very useful and allows us to differentiate various recurring configurations, from the more static forms (blocked, conflicting, which go in the direction of limitation or total compliance) up to more dynamic and flexible forms in which there is a mobile balance between needs and resources, requirements and development. The three clusters identified by our research (*Enterprising*, *Opposing* and *Condescending*) show how specificities and regularities exist at the same time in the way parents make sense of their experience of family management and care. We believe that the proposal of a semiotic-narrative interview (and at the same time clinically oriented) is useful for recognizing the subjectivity of individual parents and the specificity of their family systems, while maintaining a tension towards the identification of general trajectories of intervention and support of parental resources. This qualitative-quantitative and mix-method research intends to accept the challenge of finding forms of dynamic balance between an idiographic approach (aimed at recognizing the specificities and contingencies of individual subjects) and a nomothetic approach (aimed at searching for general and extensible forms knowledge and intervention) (De Luca Picione et al., 2019b, 2022).

Limitations and future perspectives. Finally, we have to consider a number of limitations and future perspectives of this research. The research context was that of two private ASD centers in Northern Italy where users are generally satisfied. It is important to relaunch research across different territories and contexts of different healthcare services (both public and private). This will allow for the collection of narratives of many more parental experiences and further differentiate our findings. In fact, the three clusters identified are certainly affected by the initial choice of the sample and the context. What are other possible recurring configurations in the way parents make sense of this experience? How can other configurations of parental SoG emerge?

Furthermore, from a more conceptual and methodological point of view, we have observed that the function of emotional regulation (articulated in the three modalities of *vagueness*, *discretization*, and *differentiation*) has not become part of the definition of any cluster. This lack of results for us raises absolutely important questions that need to be addressed in future research. The emotional impact that is regularly told in all the narratives in different ways (for example, in some cases as smokiness and expressible with great difficulty, in other cases as affective flooding, in still others as affective polarization and strong contrast, and finally in other cases with a wealth of nuances and affective differences) does not specify any clusters. Therefore, our critical reflection proceeds in two directions, which are not mutually exclusive: the reading of the current results and the revision of the tools of research.

The emotions expressed by the parents (and codified in the grid) do not enter in the clusters. Nevertheless, the correlation with the parental self-efficacy scale shows that there is an important relationship between the children's emotional difficulties and the clusters: Cluster A is the one that shows less difficulty in managing emotional problems children, while Cluster C is the one most in difficulty with respect to children's negative emotions. This implies that emotions are not entirely absent in our results and that therefore we need to reflect on the possible reformulation of the semi-structured interview, of the coding grid, of the regulatory function and its modalities. In previous research with respect to contexts of pediatric and chronic disease, the conceptual and methodological system on this specific dimension had shown better results, in the case of ASD the narrative expression of the parents' emotions read through our grid did not provide relevant elements, while in all the other areas it shows significant values. For us, this question remains absolutely central and is cogently placed on our research agenda.

Author Contributions "RDLP, writing of paper, narrative analysis, conceptual design of the research, adaptation of the methodology, theoretical developments, clinical reflections, supervision of the procedure of data collecting; MFF, methodology supervision, theoretical developments, clinical reflections, final reading; RB, narrative analysis, theoretical reflections; FC, data collection and analysis; AMDF, narrative analysis, theoretical reflections; BD, data collection; CF, research design conceptualization, data collection, analysis; CR, data collection; SR, statistical analysis, theoretical reflections, final reading; CS, narrative analysis, clinical reflections; GT, narrative analysis, theoretical reflections; AM, research coordinator, writing, final reading, clinical and theoretical reflections. All authors reviewed the manuscript and agree with final version."

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Data Availability Data are available from the corresponding author on reasonable request.

Declarations

Ethical Approval Ethical approval was obtained by the Research Ethics Board of the University of Parma (Protocol n. 64713).

All procedures performed in the study were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Participants were informed about the general aim of the research, the anonymity of responses and the voluntary nature of participation. All participants signed an informed consent form. No incentive was given.

Competing Interests The authors declare no competing interests.

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