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Articles

Meaning-Making Trajectories of Resilience in Narratives of Adolescents with Multiple Sclerosis

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Abstract

To date few studies deepen the construct of meaning-making at the base on the resilience process for adolescent with multiple sclerosis. Starting from a mixed-method of analysis our aim is to fill the gap in the literature by qualitatively exploring the narrative articulation of meaning-making processes highlighting specificities and differences within groups of narratives with high/medium/low resilience measured through the CYRM-28. We collected 29 narratives. The qualitative analysis shows five meaning-making processes at the base of the resilience process: *Dependence vs Autonomy*; *Reconstruction of the time lines*; *Integration of limits*; *Enlarging personal assumptive worldview*; *Connecting emotions and thought*. Compared to narratives with low/high scores, differences were evident in the way such processes were articulated. We propose a framework of central issues in the lives of adolescents with multiple sclerosis and a way to determine how these issues can be useful for developing practices and trajectories to support resilient processes.

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1. Introduction

Multiple sclerosis (MS) is an inflammatory and neurodegenerative disease of the central nervous system. The causes are unknown; however, its autoimmune nature suggests a genetic basis, and an interaction with environmental factors is generally accepted (The International MS Genetics Consortium & the Wellcome Trust Case Control Consortium, 2011).

In most cases, MS affects women at a ratio of 3 to 1, and 50% of patients are young; in recent years, the diagnosis of MS in childhood (onset before 10 years of age) and adolescence (onset between 10 and 18 years) has substantially increased (Krupp et al., 2007). Approximately, 5% of diagnoses occur before the age of 18 years (Yeh et al., 2009).

In this period of life, the onset and diagnosis of MS disease, as well as the disabilities related to it, are configured as critical experiences that interrupt the developmental continuity processes

of the young and can hinder or complicate the realization of evolutionary tasks in which the teenager and the young adult are occupied (De Luca Picione, 2015; Dicè & Freda, 2015). The main theme of life is the search for identity, culminating in adolescence (Erickson, 1994); the onset of the disease during childhood or adolescence complicates the psychosocial processes of building and negotiates one's identity.

In addition to the "chronic and degenerative" quality of MS, the progressive debilitation of bodily functions opens up constant and new challenges with respect to the phase of the life cycle that the young person is undergoing. Some studies have shown that in adolescent individuation, emotional integration and the transition from dependence to autonomy are critical changes and fundamental tasks of development, on which neurological disease exerts a profound interference (Wheland & Walker, 2009).

MS is thus defined as a critical event that complicates this series of developmental changes, inasmuch it requires continuous adaptation and the implementation of resources and skills to cope with difficulties. Nevertheless, research on the topic has primarily evaluated, in quantitative terms, the symptomatologic aspects related to the disease, including the high incidences of depression (Bonino, 2012) and anxiety (Korostil & Feistein, 2007) and the effects on cognitive functioning in youth (Quattropiani, Lenzo, & Filastro, 2018; Quattropiani et al., 2018).

The impact of the disease can extend to various domains of a person's life, as shown by the attention given to the relational and social level, which, even more in adolescence, is compromised (Thannhauser, 2009). Even if the results are not homogeneous, the most common symptom of fatigue can interfere with daily activities and the quality of life (QOL) (Gay et al., 2010).

With regard to the protective factors that play a key role in the course of the disease and that positively impact the QOL, the literature highlights the importance of being able to access external resources such as social support perceived as useful for the disease (McCabe & E.J. O'Connor, 2012).

For a good QOL in adolescence, the level of perceived parental support is crucial (Till et al., 2012), considering that the management of a chronic disease such as MS requires direct implication of the family (Hogan et al., 2007).

Only recently, the literature in this field has shown an interest in the study on the functions and processes of actively coping with such experiences. A recent study from this research group used quantitative methods (Rainone et al., 2017) and revealed how resilience plays a decisive role in facing experiences of illness and in maintaining a good QOL at an early age (Rainone et al., 2017).

1.1 Construct of Resilience

The notion of resilience refers to the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress. More specifically, resilience can be considered “a way of processing a trauma,” (Cyrułnick, 2002) attributing a personal and social meaning to the trauma.

It is not only the nature and gravity of the problematic situation experienced that determines the outcome of the experience but “the affective context, familiar and cultural, indicates the direction to give meaning to the facts” (Cyrułnick, 2002).

In the perspective of Ungar, resilience acquires the characteristics of a process of psycho-affective elaboration and the construction of the meaning of one’s own experience (Ungar, 2011, p. 23). Through this, it is possible to develop the person’s ability to access the available resources she needs to overcome challenges and to negotiate with the context in a meaningful and functional way, also increasing trust towards his/her own context of belonging (Guzman & Parrello, 2012; Di Napoli, Dolce, & Arcidiacono, 2019).

According to Ungar, resilience is the result of various interactions between individuals and their environments. The wealth of the processes of resilience can be declined in specific contexts of life through seven “tensions” (see Fig. 1) These tension can be considered general and widespread verifiable.

Ungar and colleagues (2007) indicated that adolescents interviewed in various conditions were confronted with seven tensions that can be attributed to general issues:

1. access to material goods and opportunities for education and care;
2. meaningful relationships with others, equal or adults, of the family or community;
3. identity and awareness of one’s potential;
4. values and beliefs;
5. power and control, care for others, and incisiveness;
6. adherence to local and global cultural practices, values, and beliefs; and
7. social justice, the ability to significantly affect one’s own reality, and cohesion, a sense of responsibility to contribute to a higher good and to feel part of a wider community.

Figure 1. The Seven Qualitative Aspects of Resilience (Tensions) (Ungar, 2008).

Tension	Explanation
1 – Access to material resources	Availability of financial, educational, medical and employment assistance and/or opportunities, as well as access to food, clothing and shelter
2 – Relationships	Relationships with significant others, peers and adults within one's family and community
3 – Identity	Personal and collective sense of purpose, self-appraisal of strength and weaknesses, aspirations, beliefs and values, spiritual and religious identification
4 – Power and control	Experiences of caring for one's self and others; the ability to effect change in one's social and physical environment in order to access health resources
5 – Cultural adherence	Adherence to one's local and/or global cultural practices, values and beliefs
6 – Social justice	Experiences related to finding a meaningful role in community and social equality
7 – Cohesion	Balancing one's personal interests with a sense of responsibility to the greater good, feeling a part of something larger than one's self socially and spiritually

Ungar's reflection, in a context of cultural and ecological paradigm, appears crucial because it helps us investigate the specific aspects that activate and promote processes of resilience.

In our case, they are the specific meaning-making processes of MS experience in adolescence. This means that the young patient develops the ability to live with his or her condition, implementing continuous resources of various kinds available to him.

The research question of our study is the deepening of the meaning-making processes that adolescents affected by MS articulate in dealing with own experience. We believe that the process of making meaning activates processes of elaboration, coping and negotiating with one's own condition of illness (Coulehan, 2005) that are ascribable to the more general processes of resilience.

In fact, the way in which the person is able to articulate and transform narratively their experience provides specific strategies for coping with one's own health conditions and negotiating them with others within one's own life contexts (McAdams, 2006; Taylor, 2006; McLeod, 2006).

While there have been quantitative efforts to examine how coping and resilience with diseases such as MS influences QOL (Motl & McAuley, 2009), there is limited qualitative literature to provide rich and deep descriptions of these experiences (Schneider & Wagemann, 2012). The quantitative studies enhance the understanding of "what" is happening but they have missed the intensive explorations of "how" (Patton, 2002; Riessman, 2008).

Qualitative and/or mixed methodology is preferred in research on exploring the process of resilience in various contexts and cultures (Ungar, 2003; Ungar, Lee, Callaghan, & Boothroyd, 2005; Ungar, 2011). Many qualitative studies on resilience have been conducted through narrative methodology; simultaneously, in some cases, these narrations have been considered to be protective elements, active parts of the process of resilience (Castelli, Farina, Pini, & Baventore, 2010).

The narration, intended as a device for the elaboration and articulation of the relationship with the experiences (De Luca Picione & Valsiner, 2017; De Luca Picione, Martino, & Freda, 2018; De Luca Picione, Martino, & Troisi, 2019; Martino & Freda, 2016; Martino et al., 2019) appears to be an elective study and clinical device aimed at promoting the process of resilience (Hauser, 2016).

Nevertheless, studies aimed at exploring the narrative articulation, in terms of meaning-making processes, of the processes of resilience in young with MS have been scarce. Therefore, the purposes of this study are:

- 1) To fill the gap in the literature by qualitatively exploring the narrative articulation of meaning-making processes and highlighting specificities and differences within groups of narratives with high, medium, and low resilience scores measured through the administration of the *Child and Youth Resilience Measure* (CYRM-28) questionnaire.
- 2) To provide readers with a general framework of central issues in the lives of young adolescents with MS in order to determine how these issues can be useful for developing practices and trajectories in support of the promotion of resilient processes.

2. Materials and Methods

2.1 Participants

The research was conducted at the Multiple Sclerosis Center, located in the Neurology Department of the Federico II University Hospital. The Center aims at welcoming the person suffering from MS and their family and offers a network of integrated services to accompany them in the care path. The research was approved by the Ethical Committee of the Hospital.

The sample comprised 29 adolescents, with an average age of 21 years and diagnosis of relapsing–remitting MS that started at the average age of 4 years (min. 2; max. 10; d.s. 2.06). The participants were asked to sign the informed consensus and authorization for data treatment. The participation was voluntary and anonymity was guaranteed according to the current laws.

The data collection was conducted by a researcher with a clinical psychological background. The meetings with adolescents took place in an *ad hoc* room of the Neurology Department.

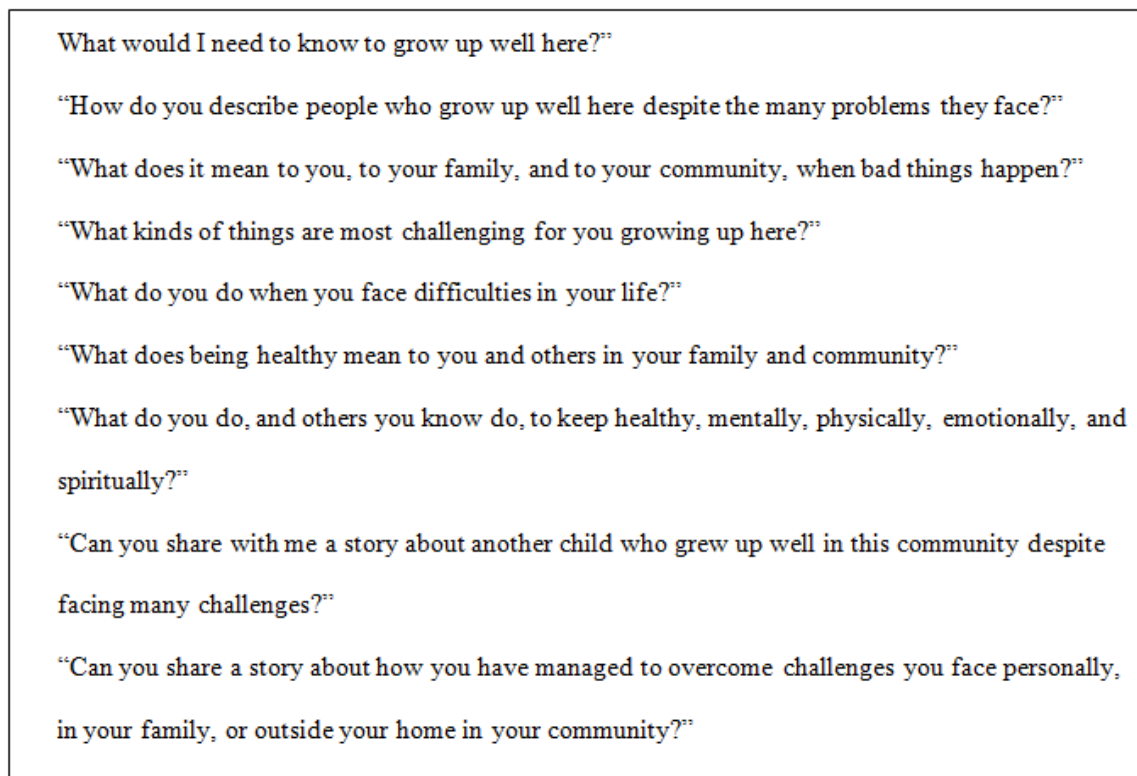
2.2 Tools

First, we administered the CYRM questionnaire. CYRM-28, a quantitative version, comprises 28 items according to a Likert scale based on five points. It evaluates the competence to use particular types of resources in dealing with a critical situation.

It is a measure of the resources (individual, relational, communal, and cultural) available to individuals that may bolster their resilience. The measure was developed as part of the International Resilience Project at the Resilience Research Centre in 14 communities worldwide (Ungar et al., 2011). This tool allowed us to assign a resilience score to each participant.

Thereafter, we recorded the narrations of illness experience for each participant through a qualitative interview based on the Qualitative Interview Guide (Ungar & Liebenberg, 2011). At the core of the interview schedule, there were nine “catalyst” questions. (Fig. 2)

Figure 2. The Nine Catalyst Question (Ungar et al., 2011).



2.3 Data Analysis Method

We started from the scoring of the 29 questionnaires of CYRM-28 and sort it in three groups: high, medium and low scores. Since the tool had no threshold cut-off, the high, medium, and

low values were based on 33rd, 63rd, and 96th percentiles to keep the groups numerically homogeneous. Our aim was to divide corresponding narratives in three groups. Therefore, we obtained 9 high resilience narratives, 9 medium resilience narratives, and 11 low resilience narratives.

For the analysis of narrative interviews, we used the method developed by Auerbach and Silverstein (2003). That method allows researchers to create a theoretical narrative based on meaning-making and articulation of resilience processes. This method is particularly suitable to explore meaning-making processes following a traumatic event (Salick & Auerbach, 2006). It allows researchers to develop a category system organizing the content of the rough text into themes derived from recurrent concepts according to theoretical constructs.

To sum up, the first level of analysis was the reading of narratives through theoretical sensitivity offered by the seven tensions of resilience. We were able to define the experience domains in which resilience processes are described.

The second level of analysis was aimed at the individuation of specific themes told in the narratives. Thereafter, we developed a matching plan between the abstract and specific dimensions, highlighting theoretical constructs of meaning-making. After identifying them, we arranged them in a theoretical narrative according to the stories told by the participants in terms of theoretical constructs and their themes (De Luca Picione, 2015).

We started with the analysis of narratives from the groups with medium score of resilience through the CYRM-28 questionnaire. It highlighted the general trajectories of meaning-making processes (theoretical constructs) and founded the resilience strategies more or less effective (themes). Such process of analysis allowed us to identify, according to the chosen methodology, general and abstract meaning-making theoretical constructs useful for the reading of narratives in the groups with low and high resilience scores obtained using CYRM-28.

3. Results

3.1 Analysis of medium resilience score narratives

Here, we present the analysis results of narratives from groups with medium score (see Tab. 1), and we show the various ways in which these theoretical constructs articulated in narratives from groups with low and high resilience scores. Remarkably, in the phase of confrontation between narratives from groups with low and high resilience scores, such constructs proved to be able to read all the narratives and show the various ways to articulate the resilience strategies more or less effectively narratively.

Table 1. Meaning-Making trajectories of resilience in narratives of adolescent with MS having medium level of resilience

The need between dependence and autonomy	Reconstruction of the time lines	Integration of limits	Enlarging personal assumptive worldview	Connecting emotions and thought
The crisis of social relationships	The illness does not wait	The body speaks	The illness as category of the Possible	Emotion as promoter of agency
The family relationship between safety base and regression	The collapsed Future		The social function as carrier of changing	

A) Dependency vs Autonomy

The first theoretical construct that emerges from the analysis of narratives highlights the attempt to construct a primary form of meaning around the traumatic experience of diagnosis. In the *hic et nunc* of the narration, a renewed request for meaning emerges (Freda, Monteagudo, & Esposito, 2016). This construct highlights the searching for border (De Luca Picione & Valsiner, 2015) with respect to the process of confusion, loss, and disintegration that the diagnosis of such pathology introduces into the life of an adolescent. The diagnosis places the adolescent in relationship with the regressive movement. In salience, we find the relationship between self and others and the conflict between autonomy and dependency (which recalls the conceptual tensions of cohesion and control) in a intertwined context of development and illness experience.

- The crisis of social relationships

The diagnosis is narratively configured as a profound loss of one's identity and as social isolation that interrupts the preordained flow of one's life. The illness in the *hic et nunc* of the narrative reactivates the global sense of loss experienced at the time of diagnosis by acquiring the meaning of a limitation. The adolescent narratively articulates the search for a form of management of their need/right of autonomy by putting into words all the unresolved ambivalence entailed in this dichotomy. "I did my first year of university in Siena, because I wanted to stay there, then what happened, and when I came back to Siena it was like living a bad time in my life and as a

result I wanted to go back to Naples so I had to make the transfer the only difficulty I have now with regard to the disease is to talk about it ... now I'm trying to recover, because at the beginning it was hard for me, I thought meeting them ask me: 'Why, how come?'. I did not want to say what had happened, there was a sort of wall with people on my part, this was one of the biggest difficulties”.

- The family relationship between safety base and regression

This theme articulates the relationship between the adolescent with MS and his family of origin. On the one hand, the family, understood as the primary emotional context, is symbolized as a compass and support in the fulfillment of the treatment process. On the other hand, it can also symbolized as an obstacle. The narrative in fact re-enacts the ambivalence and, in some respects, the anger connected to the need to feel a secure base and to the regression that this implies with respect to the development tasks. The proximity of the family, symbolized as a control, takes the form of suffocation. Such an issue introduces the crucial role of the development of autonomy for adolescent patients. This is understood as a psycho-social process of developing the ability to autonomously manage therapeutic practices, healthy behaviors, and care needs. Furthermore it is implied a development of psycho-affective processes facing the difficulties of everyday life (Scotto di Luzio, Procentese, & Guilett-Descas, 2019; Procentese, Gatti, & Falanga, 2019). Here, we can see some of Ungar's tensions at work: relationships, identity, and power and control. Simultaneously, however, the narrative process allows us to identify an intermediate area of differentiation and discretization of the subjective experience in which we can “entrust ourselves to the other” and “collaborate in the management of our care”. Therefore, on this plan, we try to find solutions and possible compromises regarding the tension of access to resources. Acknowledging the disease as a limit allows, through this meaning-making process, to take an active role in the first person, in which one is no longer completely dependent on the care of others.

“... My parents are a bit 'special', are petulant about the illness, in the sense that every morning I take the drug and every morning my mother asks me if I got it, this is heavy, it is unbearable, I now take it in spontaneously, I get up, I take the drug, I do it as if it were a routine, I do not mind, but when they ask me if I got it, it becomes heavy, it is heavy to feel controlled, to see them anxious for this I have ...When they see that I do not feel well, they say 'do not move, stay still, do not get tired'...”

B) Reconstructing the Time Lines

The second theoretical construct that emerges from the narratives refers to the process of constructing meaning that mediates the relationship between processes of continuity and

discontinuity of life. This meaning function attempts to articulate the lines of subjective and relational temporality (Freda, De Luca Picione, & Martino 2015; De Luca Picione, Martino, & Freda, 2017). In fact, inscribing one's own experience within "negotiable temporal frames" means to articulate the tensions of identity, relationality, agency, cohesion, and power and control. The harmonization of the temporal trajectories supports the attempt to construct a time of illness within which life tries to take its place. The narration is based on a temporality where the present time is in the foreground (with needs and tasks) fading aspects of the future that are not yet articulated in a new continuity. In general terms, we can say that the specificity of MS, including irreversibility, chronicity, and possible progressiveness, makes the temporal aspects of the processes of constructing the meaning of one's experience particularly salient since it must be compared with a past that it will no longer be able to return and with a future whose symbolization is realized through uncertain scenarios. The present time presents itself as a temporal horizon, in which the young patient can take many different subjective positions within a continuum that goes from the regret of the past, to the fatigue of the present, to personal and social commitment to found a different future.

- The illness does not wait

This theme articulates the relationship that the youth with MS has with the daily management of the illness. The illness impose its temporal priorities. The illness is meant as a silent illness that "walks inside" where the pharmacological care and daily commitment to the body, as well as the medical checks to observe the progress, represent the attempt to make it manageable and above all observable. Here the tension of resilience of "access to resources" is recalled, specifically declined in terms of medical care, drug administration, and continuous diagnostic checks. The processes of resilience of the young patient are also built through the confrontation with the medical plan and the resources/constraints that it offers. In fact, the course of the illness seems to present itself more to the medical view. This process of meaning-making absorbs a large part of personal experience and subjective experiences within frames of medicalized sense. At present, the illness is saturated with the time of young people who are aligned with the medical prescriptions if they are able to occupy it even if they leave empty other possible relational spaces, social coexistence, and sharing of interests.

"So I cannot wait to do the MRI to see my condition. When I have to do the injection of interferon, even if I've been doing it for months, every time it takes me a blow of courage because I already know that hurts me, there are many people who postpone it until the next day, but I, I have to do at that moment, there must always be the moment when I have to do it, so it is better to take my mind off right away and see".

- The collapsed future

In a diachronic and vertical perspective of time, this theme condenses aspects of concentration on strategies in the present not connected to the past and the future. The future is narratively articulated in terms of possible spaces and horizons but anchored to the current state of illness. Here the tensions of “cohesion” and “cultural adherence” show all their importance and difficulty of realization at the same time. Within a present (totally circumscribed by the experience of illness) symbolized as pervasive, the future appears to be difficult to symbolize in terms of investment in one’s own person, social relationships, and cultural values and ideals because they are doubtful about the progression of the illness.

“Yes, because as we live today we need to play down on everything and move forward thinking about the present and not thinking about the future or the past, but living day by day because unfortunately these illnesses are going really bad and unfortunately we have to take it as he comes there day by day”.

- Integration of Limits

The third theoretical construct that emerges from the narratives refers to the construction process related to the relationship of integration possible with the experience of the limit connected to the illness. This construct shows how the tensions of the resilience processes (namely, access to material resources, relationships, identity, power and control, cultural adherence, social justice, and cohesion) are fully compared with the two main themes of the body and social relations. Recognizing their difficulties and limitations connected to the illness establishes the resilient possibility of connecting in a more congruent way with their needs and finding new solutions for development, adaptation, and coping achievable and feasible in everyday life.

- The body speaks

This theme articulates the relationship between the adolescent with MS and his/her sick body. This brings the body into salience symbolized as a hegemon, not to be challenged but to be listened to. This issue is narratively described as the possibility of placing one’s own body and its signals, its needs, and themes at the center. The narrative articulation of this relationship populates the possibility of a connection, a relationship more respectful of the times of the body, as an effective strategy of mediation and organization of relationships.

This theme highlights the relationship between self and body, its fragility, and the articulation of a connection with a disease that appears as “invisible” but “perceptible” in its effects/symptoms. This process of sensemaking attempts to articulate a compromise with the

illness that is conceived as the one that dictates the rules of the game and places needs and constraints.

This topic introduces the importance of a relationship (in the resilient terms of “negotiation”) with one’s own body capable of being felt as sick and of orientation of one’s resilient strategies (about access to resources, power and control, relationships, and identity).

“ but I realized that I have to rest because I noticed that after I'm worse ... initially tiredness, if I bring a water box I get tired, even mental fatigue, I get a headache. A little 'discourage' me when I feel tired without having done anything, but I sit 5 min I see if I can recover”.

- Enlarging Personal Assumptive Worldview

The fourth theoretical construct emphasizes meaning-making processes that articulate the relationship with its own premises on the world and its own way of interpreting it pre- and post-diagnosis and treatment. We are precisely dealing with the tensions of identity, cohesion, and cultural adherence as the resilience processes confronted through the following themes precisely, with the possibility of transforming one’s perspective on experience and on the values that guide it and ultimately seeing oneself differently.

The illness imposes itself as a signifier that transforms and broadens its interpretative patterns on the world to accommodate the illness and fragility that connects it as a thinkable and possible category of human existence to integrate this event in personal vision of world.

- Illness as Category of Possible

This theme re-enacts, in the *hic et nunc* of the narration, the request for meaning emerged following the communication of the diagnosis “why me?” (Russell, White, & White, 2006). The narration makes it possible to question the impossibility of explaining the reasons for one’s illness and of the difficulty in dealing with the diagnosis of MS.

In this way, the narration allows us to make something unspeakable (Stern, 1997) and make possible the absence of meaning of the experience of illness to observe the potential of a new interpretation of the world and of ourselves. This is precisely the domain in which the narrative processes of meaning-making are confronted with the resilient tension of cohesion (meaning aspects of spirituality).

To derogate from the search for meaning on the illness does not mean to renounce confronting the experience but to explore and promote the possibility of going down into battle and making choices. This modality of relationship with the diagnosis appears to be a way to articulate resilient strategies.

“Let's say that compared to my situation, at the beginning I did not take it well, I did not understand why among billions of people just me, then I realized that they are questions to which the answer cannot give and better that you leave them otherwise you will only ruin your thoughts, think other things...

When I stopped wondering why this condemnation had happened to me, I did not stop living but surprisingly I began to find new meaning to the things I was doing and to look at new things that I had never noticed before”.

- Social Function as a Carrier of Change

This issue articulates the importance, in the relationship with its categories on the world, of the social function in the construction of resilient strategies, where the mirroring and sharing with one's peers is fundamental to promote social inclusion, well-being, and increased QOL.

Relationship and social justice tensions are a central reference in these meaning-making narrative processes.

This plan, which we can metaphorically define as a real reservoir of energy, connects aspects linked to the promotion of optimistic strategies of relationship with life and of sharing with others.

“In the various associative environments, I have created links with some guys who follow me everywhere at concerts, my roommate, I have many friends each is important for a different reason, to share, to forget the problem”.

- Connecting Emotions and Thought

The fifth theoretical construct is based on the process of connection between emotions and thought. The narrative articulation of the relationship between painful emotion and thought becomes a process of reflective thought capable of modulating emotional processes and affective states.

The emotion that is re-enacted in the *hic et nunc* of the narrative does not paralyze but becomes thinkable and is placed at the service of oneself and one's own well-being.

The dimension of connection between reflexive thought and emotional processes is shown as another area of important development of resilience strategies (cohesion, power and control, and cultural adherence) with regard to the experience of illness.

- Emotion as a Promoter of Agency

This theme narratively connects aspects related to the direct relationship with fear and terror as a movement toward care. The recognition of one's emotions allows the development of the agency (Dicè, Dolce, & Freda, 2016).

Fear does not paralyze anymore but activates actions and resolutions. Emotional cues allow young patient to support health and the functional relationship with life (resilient tension of power and control).

“I felt the fear but if you think she wins ... Instead I got guided by her, I move in time like this ... last year I had to do a knee operation, my mother said oh well then you do it, but I said no, now, because I want to do, the syringe, I was afraid of the needle, I had to do the epidural, I said : “Dr., Do what you want, just do not let me see the needle.

I find a way to deal with it, even if I do not want to face it, I find a way, any way, but I face the same ... I'm terrified ... I faced it, it was hard, looking back it was hard ... but at the moment the affront is so”.

3.2 A comparison between high-resilience narratives and low-resilience narratives

If the processes of meaning construction highlighted in the narratives with medium resilience are included both in the narrations with high resilience and in those with low resilience, we can highlight different and peculiar aspects of the way of articulating these processes within groups of different narratives.

Narratives with high resilience scores

In particular, the different and peculiar aspects highlighting the high level of resilience are linked to the way of narratively articulating resilience strategies starting from three processes of signification. They are as follows: dependence vs autonomy; the integration of limits; reconstructing the timelines.

- Dependence vs Autonomy

We observe that narrators with high resilience scores articulate a relationship with the family that is no longer symbolized as an intrusive and controlling object but as a constructive resource driven toward life to be protected and inspired. Ungar's resilient tensions (relationships, access to resources, social justice, and power and control) find interesting narrative developments.

In fact, the narrative articulation of this theme highlights a more flexible process of signification capable of supporting crucial meanings: to resolve the dichotomy between dependence and autonomy; to recognize the contribution of the family to their well-being; to actively position

oneself in the relationship with the parents, where the boundary represents an area that can be contemplated.

The concerns and the fear connected to situations of dependency form through the putting into words that makes them communicable and discussable in the relationship with loved ones wherein autonomy does not give way to substitution. It seems to be articulated in the service of maintaining boundaries and recognizing roles and functions.

“I do it for them but also for me and to find my freedom, I felt different, I was afraid that they noticed now no I speak quietly so now it's not limiting I talk about it Yes, with the family First of all, with words, I speak and I try to get to the problem, I see how to find the solutions”.

- The integration of the limits

Regarding this construct, we observe how the various signals of the body are narrated with vividness and precision. The meaning-making processes expressed in these reports tell how listening to the body and its needs can be calibrated with one's young life with MS. There appear on the illness new spaces of thinkability of everyday forms of management, competence and control, integration of vital areas, and new less-limiting aspects of one's identity.

“I'm like that, before I was terrified of the needle, now it's me that I give myself the injection, it's not a satisfaction but a goal, as I have faced up to now my concern was being not able to go anywhere because anyway these injections were a bond that I had to bring instead I was a month out and I successfully managed it, I realized that they are not a constraint but just something to remember ”

It is also important to highlight how this group of narratives with high resilience scores deals with the issue of the temporality of one's own experience. Here, some decisive tensions of resilience (identity, relationships, cohesion, and cultural adherence) find narrative articulations based on the recovery of temporal frames of one's own experience of illness that they manage to reintegrate one's own history with future planning.

We find a watershed between the past time of discovery and diagnosis of disease and the future time. Past, present, and future become thinkable and manageable. The future is symbolized in terms of projects, desires, and hopes, appearing to be most possible. The disease becomes a part of oneself with whom to live through the adoption of strategies. The disease is present and requires to be considered, but this does not mean abandoning one's own projects.

“My goal now is my son, after the diagnosis was given an explanation to my fatigue, I say oh well does not depend on me, if I have to deal with my son, I do, while before I threw myself on the couch and sleep, now I sleep when he sleeps.

Proposals for the future? Find a job ...”

Narratives with low resilience scores

Referring to the narratives with low resilience, we found particularly significant differences that polarize the following meaning-making constructs: Dependence vs Autonomy; connection between emotion and thought; reconstructing the timelines.

In general, in the narratives with low resilience scores, we see how the tensions become dimensions of conflict, toward which the young patient risks to get bogged down painfully.

- Dependence vs Autonomy.

With respect to this meaning-making process, we observe a rigid position blocked at the time of communication of the diagnosis. You find that an ambivalent and ambiguous position based on the conflict with family members is maintained.

Parents are considered as simultaneously asphyxiating and non-caring and indifferent presences, and the disease is seen as a burden (a burden too heavy to carry) and it is better not to talk about it.

“I do not know, I've never been well because in any case in my life I have always suffered both with my family ... it seems that it does not matter ...

They do not even know, they are not comfortable with themselves since... how can they be comfortable with me since the everyday life is hell... My parents command about everything ... it's not a family, my family...”

- Connection between emotion and thought

The connection process does not seem to exist. Emotion, as a function of constructing thought and an indication of the relationship among oneself, reality, and the world, does not seem to fulfill this function. The resilient tensions of power and control and access to resources are related to the impoverishment of the narrative connection process.

In fact, the narratives in this group are characterized by a poor passage to agency and self-experimentation in the world. In these narratives, the thinking does not always appear as a process of elaboration capable of promoting the development of action and the transformation of one's own positioning.

Rather, it often takes the form of a remaining brooding behavior. There are ideational fixedness and self-commiseration. Several narrators were also able to recognize this difficulty and cognitive impasse. It therefore seems that lived emotions, rather than translating into agentive

resources, become affective conditions to be observed, recognized, and complained but without any possibility of being modified.

“Many people are not like me, they would not react in the same way. In the end, if I had to describe myself, I would describe myself as optimistic, but I'm very anxious sometimes, for example, when I went to the station while I was at school I was thinking, ‘What if I'm late?’ I tend to think too much”

- Reconstruction of the timelines

Meaning-making function is narratively articulated as immobile. Within this articulation, we not only find the presence of a pervasive present but also a history of the diagnosis that is re-enacted in the present. The resilient tension of cohesion and identity does not seem to open up to new scenarios of trust, hope, values, and optimism.

The past understood as “what happened to me” is re-enacted in the present, reporting the origin of the disease change, and it is perpetuated day by day. In addition, we mention the narrative quality of a nostalgic future, now lost forever, that emerges as the time with dreams of which it is impossible to imagine the feasibility.

The experience fails to project itself into the future in terms of desire, the present is pervaded by fear, and the past becomes a container of old hopes and remittances that cannot be processed.

“I always think of the disease in a negative way ...

if I'm okay I say I'm sick because it's just the minimum there are a few days when I'm calm with my mind because in any case I think about the past things I do not think about the future or the present but always in the past to what happened to me. I live a day a day and I always think of the past.”

4. Conclusions and future implications

The analysis of narrations and meaning-making processes provides important information about the resilience processes implemented in the experience of MS diagnosed in adolescence.

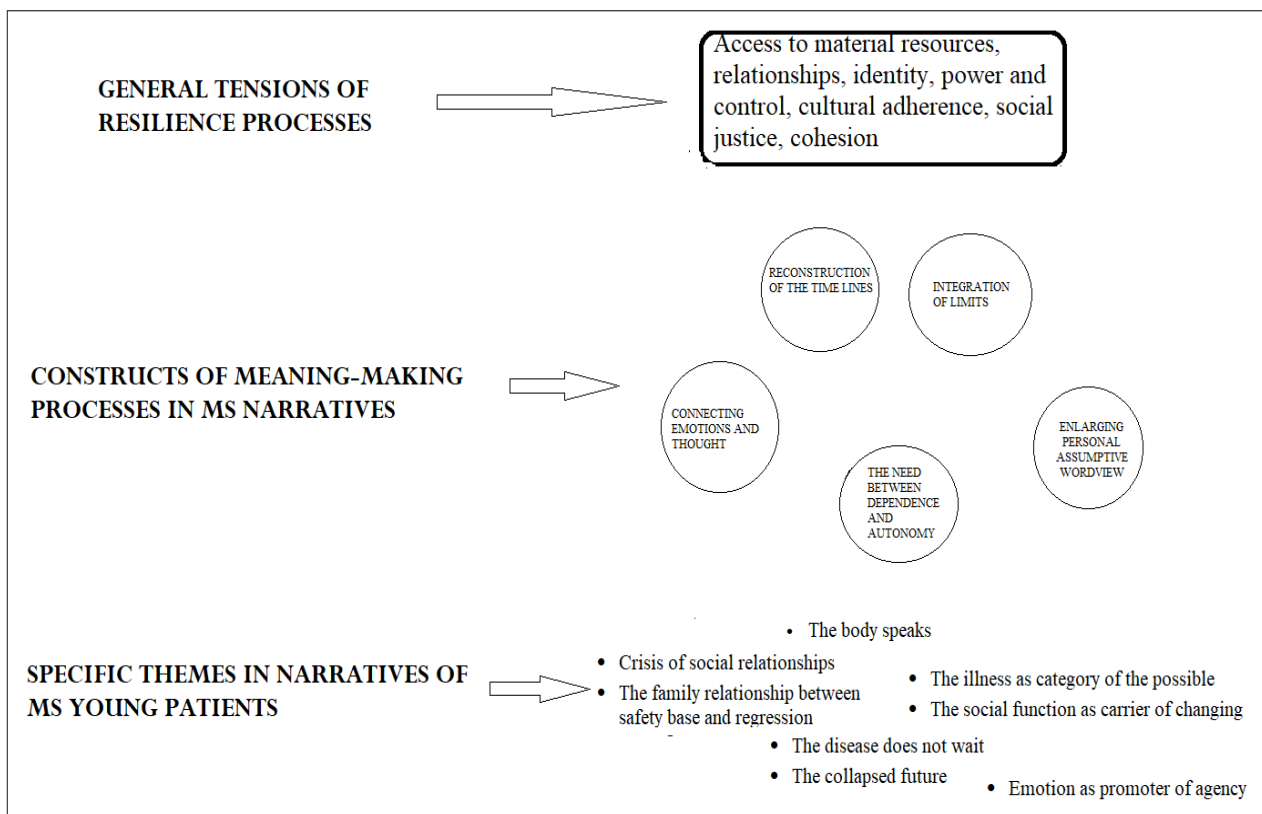
Our research identifies the specific meaning-making processes that play central roles in the development of resilience. Consistent with the assumptions of the ecological perspective of the construct of resilience (Ungar, 2012), that has led us to compare the transversal and general tensions of the resilience processes (access to material resources, relationships, identity, power and control, cultural adherence, social justice, and cohesion) to the specificities of the context

of MS in adolescence and to the vicissitude of the subjective experiences of young patients expressed through the narration of their experiences.

Furthermore, on the one hand, the quantitative side was able to identify and measure levels of resilience through the CYRM-28 questionnaire; on the other hand, the qualitative side allowed us to compare the narrative processes and their articulation of young patients in relation to the resilience scores (we have divided the 29 narratives into three groups: low, medium, and high scores according to a division in percentiles).

The possibility of creating and developing resilience processes is linked to the subjective way one's own life domains are negotiated with other people within contexts of belonging. Specifically, in MS starting at a young age, the resilience processes are required for the development and improvement of health practices, promotion of multilevel well-being (Di Martino et al. 2019), and increase of the QOL.

Figure III. Resilient tensions and specific themes in multiple sclerosis narrators



The onset of the MS, in the words of the narrators, appears not only as a physiological invalidation of the body but also as a condition of great difficulty for one's own identity and relational bonds. The MS during adolescence becomes a strong constraint/limit and requires the construction of specific forms of negotiation in meaningful relationships: family, love, schooling, and equality. The identity construction of one's self-image and the prediction of a

difficult “future already written” poses a complex psychosocial challenge: to juggle the tendency to take refuge in relationships of dependence and passivity; to commit to building and defining areas of autonomy; and to preserve social contexts of interests and pleasure.

MS in adolescence seems to introduce areas of intense ambivalence, especially in the relationship with the family. The resilience processes configure domains of development in the area of relationality, power and control, and access to resources.

Our analysis shows that the psychological reworking of emotional ambivalence toward the family is a crucial issue. The family is both a reference point and one’s own security, but it is also the cage, the symbol of one’s own dependence. If that ambivalence may seem “normal” in adolescence, however, it constitutes a sensitive and neuralgic point in the adolescence of a patient with a chronic disease. This is because the process of self-empowerment and responsibility with respect to oneself and one’s own health remains inextricably linked to specific needs of care and therapy (read tension of access to resources) in which the family maintains a great centrality.

In the narratives of adolescents with low resilience, the meaning-making processes of one’s own experience emphasize situations of great suffering connected to stasis and conflict of identity (“*I am sick?*”), of feelings and emotions connected to illness (“*I am afraid?*”), of intense ambivalence toward the family (“*I am angry with my family/I need my family?*”). Identity, family and social relationships, and emotional experiences are blocked, firm, incapable of development, and these contemplate new possibilities of life. Time appears suspended and blocked. In reference to the tensions of cohesion and power and control, the attitude of hope as well as trust in future values and ideals are not traceable. From the analysis of the narratives with high resilience, it emerges how the ability to construct areas of autonomy in the management of the disease represents a central trajectory in the development of active and resilient strategies for coping. This is possible, as can be seen from the narratives, through the integration of emotions and thoughts.

We think this is an important point: the tensions of the resilience of power and control and access to resources are linked to the processes of recognition and processing and sharing of one’s feelings and emotions. These young patients, with high scores of resilience, tell us that emotions must be experienced and not avoided; only this reflexive and integrative attitude allows an integration of one’s own limits and resources.

The emotional resonances and sensations of the body can become valuable clues to create new effective strategies. As observed in the narratives with high resilience, the virtuous processes of facing the difficulties connected to one’s own illness do not represent an absolute and static condition but a process of elaboration and construction of the sense of one’s own agentic

experience (Rainone et al., 2017). Time is not blocked, but it shows itself as dynamic set of trajectories, with the possibility of transformation. The young narrators with high resilience recognize the difficulty of having received the diagnosis and of feeling bewildered and frightened (recognizing that they are still now). Yet, they acknowledge some transformations (a transition between a first and a post time in search of more virtuous strategies) connected:

- a) to feel their emotions and to put them at the service of their thoughts, communications, and actions;
- b) to allow the construction of a flexible border that regulates “autonomy” and “collaboration” without leading to the area of substitution and absence of borders (in terms of dependence or total reliance)

This allows us to support the agentic initiative and the construction and maintenance of social bonds through which to share areas of life that are not only medicalized. We therefore believe that the adolescent can experiment herself/himself as more and more autonomously in the same medical relationship, moving from a child mediated/controlled by the parents toward new more adult positions of active subject/holder of the medical relationship (Rainone et al., 2017; De Luca Picione, Martino & Freda, 2018).

The various ways of articulating narrative processes in relation to various levels of resilience can therefore provide us with valuable information and indications for the planning of supportive processes with young MS patients. In the narrations with low resilience scores, the meaning-making processes appear in a static, stiffened, and blocked condition that cannot be processed psychically and cannot be transformed. In the narrations with high resilience scores, we observe meaning-making processes that take the form of flexible, dynamic trajectories able to transform themselves and to find new solutions and adaptations.

We can highlight interesting implications for the development of interventions in the field of health psychology toward chronic adolescent patients and their families (Riccio, Hernandez, & Perrella, 2018). In fact, considering the narrative representation of the disease and the specific ways of constructing the meaning of the experience of illness allows us to be able to direct and facilitate processes of emotional containment (in the acute phases or reception of the diagnosis) and reflexive processing (in the following phases) to the young patient and to the whole family system to mobilize the narrative processes toward their transformation and not hardening on some fixed positions.

In conclusion, a good resilient competence in the MS experience appears connected to the meaning-making processes enabling one to sustain:

- 1) the construction of intermediate and more discretized areas of the relationship with the subjective experience of illness, in which thoughts and emotions are interconnected;
- 2) the construction of autonomous agentive areas within other significant persons (caregivers, parents, relatives, doctors, friends, and partners) support without replacing one's own commitment and responsibility;
- 3) the identification of a time of care that, from a horizontal perspective, is integrated with the time of life and tries to reconnect the past–present–future with a vertical perspective;
- 4) the integration of the limit as recognition of set of constraints and resources with whom to confront for an expansion of one's own premises on the world.

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