Multiple Sclerosis And Maternity: A Psychological Explorative Qualitative Research

Maria Carlino  
*University of Naples Federico II, mariacarlino@alice.it*

Roberta Lanzillo  
*University Hospital of Naples Federico II, robertalanzillo@libero.it*

Alessandro Chiodi  
*University Hospital of Naples Federico II, alessandro.chiodi@unina.it*

Roberto Vitelli  
*University Hospital of Naples Federico II, rvitelli@unina.it*

Luigi Lavorgna  
*University of Campania “Luigi Vanvitelli”, luigi.lavorgna@policliniconapoli.it*

*See next page for additional authors*

Follow this and additional works at: [https://nsuworks.nova.edu/tqr](https://nsuworks.nova.edu/tqr)

Part of the [Social Statistics Commons](https://nsuworks.nova.edu/tqr)

**Recommended APA Citation**

Carlino, M., Lanzillo, R., Chiodi, A., Vitelli, R., Lavorgna, L., Brescia Morra, V., & Margherita, G. (2020). Multiple Sclerosis And Maternity: A Psychological Explorative Qualitative Research. *The Qualitative Report, 25*(5), 1279-1292. [https://doi.org/10.46743/2160-3715/2020.4103](https://doi.org/10.46743/2160-3715/2020.4103)

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.
Multiple Sclerosis And Maternity: A Psychological Explorative Qualitative Research

Abstract
Considering women living with multiple sclerosis (MS), motherhood may represent a complicated event. Our aim in this study is to explore the personal meanings related to maternity and illness in women living with this disease. We have involved twenty women suffering from MS and we have administered an open interview introduced by a trigger question as a prompt aimed to elicit a narrative of their experience of illness, wishes, doubts, fears and life-projects with regard to motherhood. The interviews were audio-recorded and transcribed verbatim in order to carry out an analysis of the textual corpus. We have performed the textual analysis of the transcribed interviews through the T-LAB software. Performing a cluster analysis, four thematic clusters emerged: Daily Pain, Relationship with Health Care Services, Closing of a Circle and Family Role. We have interpreted the relationship between these themes using factorial mapping through 3 meaning vectors, representative of the following dynamics: From Concrete to Abstract; From Life-Project to Relapse; From Health Agencies to Family Support. All these meaning-vectors seem to describe the relationship between maternity and illness. Some aspects, as the presence of a stable partner or knowing diagnosis for more than ten years, might represent supporting factors for a project of motherhood. Starting from the results obtained, we provide some proposals for the definition of goals and strategies of psychological counselling within the Health Care Services.

Keywords
Multiple Sclerosis, Maternity, Narratives

Creative Commons License
This work is licensed under a Creative Commons Attribution-Noncommercial-Share Alike 4.0 International License.

Authors
Maria Carlino, Roberta Lanzillo, Alessandro Chiodi, Roberto Vitelli, Luigi Lavorgna, Vincenzo Brescia Morra, and Giorgia Margherita

This article is available in The Qualitative Report: https://nsuworks.nova.edu/tqr/vol25/iss5/8
Multiple Sclerosis and Maternity: A Psychological Explorative Qualitative Research

Maria Carlino, Roberta Lanzillo, Alessandro Chiodi, and Roberto Vitelli
University of Naples Federico II, Italia

Luigi Lavorgna
University of Campania “Luigi Vanvitelli”, Italia

Vincenzo Brescia Morra, and Giorgia Margherita
University of Naples Federico II, Italia

Considering women living with multiple sclerosis (MS), motherhood may represent a complicated event. Our aim in this study is to explore the personal meanings related to maternity and illness in women living with this disease. We have involved twenty women suffering from MS and we have administered an open interview introduced by a trigger question as a prompt aimed to elicit a narrative of their experience of illness, wishes, doubts, fears and life-projects with regard to motherhood. The interviews were audio-recorded and transcribed verbatim in order to carry out an analysis of the textual corpus. We have performed the textual analysis of the transcribed interviews through the T-LAB software. Performing a cluster analysis, four thematic clusters emerged: Daily Pain, Relationship with Health Care Services, Closing of a Circle and Family Role. We have interpreted the relationship between these themes using factorial mapping through 3 meaning vectors, representative of the following dynamics: From Concrete to Abstract; From Life-Project to Relapse; From Health Agencies to Family Support. All these meaning-vectors seem to describe the relationship between maternity and illness. Some aspects, as the presence of a stable partner or knowing diagnosis for more than ten years, might represent supporting factors for a project of motherhood. Starting from the results obtained, we provide some proposals for the definition of goals and strategies of psychological counselling within the Health Care Services.

Keywords: Multiple Sclerosis, Maternity, Narratives

Introduction

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system and the second leading cause of neurological disability in young adults, with a mean age at onset of 28 years (Weinshenker et al., 1989) and a female/male ratio of 3/1 (Trojano et al., 2012).

MS is characterized by a range of signs and symptoms, including physical (e.g., double vision, blindness in one eye, muscle weakness, trouble with sensation, or trouble with motor coordination), psychological difficulties or psychiatric disorders, with a high variability between subjects and over time.

For women living with such an unpredictable chronic disease as MS, maternity is a highly complicated passage in their life course (Grue & Lærum, 2002). In addition, although this disease does not generally compromise procreative capacities, some medications can affect...
and hinder them (Cavalla et al., 2006). As shown in a previous online survey of ours, MS diagnosis impacts dramatically on the life project of women living with MS who often renounce to have children because of the disease and in pro-parenthood MS subjects it impacts especially on having the second child (Lavorgna et al., 2019).

Usually, women living with MS may face greater difficulties in the assisted reproduction path (Hellwig & Correale, 2013). From a clinical point of view, on occasion of pregnancies it is often possible to observe a relief of symptoms of disease while during the first postpartum trimester there is a high risk of relapse (Finkelsztejn, Brooks, Paschoal, & Fragoso, 2011; Langer-Gould & Beaber, 2013).

We consider motherhood as an existential event, a “critical” process (Bibring, Dwyer, Huntington, & Valenstein, 1961; Bornemark & Smith, 2016) that implies an inner psychological restructuring work aimed at modifying affective and cognitive representational aspects of the Self, the Other and Relationships (Houvouras, 2006). Women have to gradually redefine the intersubjective schemas and intra-psychic equilibrium as well as the couple's dynamics (Ammaniti, Tambelli, & Odorisio, 2013; Ferraro & Nunziante Cesàro, 1985; Soifer, 1985; Stern, 1995).

Up until now research concerning MS and representations of motherhood are still very poor (Payne & McPherson, 2010). Some researchers have explored concerns and fears that women may have with regard to possible motherhood: the expectations for the negative effects of a drug suspension on their own health status; the representation, in fantasy, of a “defective child” they could give birth to because their disease (Oksenberg, Baranzini, Barcellos, & Hauser, 2001), feeling of lacking maternal abilities (Birk & Kalb, 1992), fear for possible aversive social reactions and finally, doubts about the right time for motherhood (Alwan et al., 2012; Prunty, Sharpe, Butow, & Fulcher, 2008).

Our interest started from a long time psychological clinical experience carried out in a hospital setting with women who had been diagnosed with MS. Patients we have encountered showed different degrees of seriousness of illness and several times they differently faced up the idea of motherhood. Starting from our clinical experience, from a psychodynamic perspective we decided to explore in depth the symbolic and emotional nature of meaning making processes that characterize the experience of pregnancy of women living with chronic illnesses. Within the context of fairly wide research into narratives on motherhood (Carlino & Margherita, 2016; Margherita, Carlino, & Tessitore, 2017; Margherita et al., 2017; Margherita, Gargiulo, & Martino, 2015; Tessitore & Margherita, 2019) our aim was to investigate the personal meanings related to maternity and illness in women living with this disease. Up until now, no studies conducted with women with MS have been carried out on this topic.

Still today, only a minority of women living with MS are counseled to plan pregnancy (Lavorgna et al., 2019) although it may represent a remarkable passage in their life. A better knowledge of the psychological features related to this issue may help to define goals and strategies of psychological counselling within the Health Care Services.

Methods and Procedures

We chose to adopt an explorative and qualitative methodology, based on a thematic analysis, already employed in some previous works of us (Margherita, Gargiulo & Caffieri, in press; Martino et al., 2019). This methodology allows researchers to start from narratives, and, through a bottom up analysis, it provides specific ways to identify their main themes. We can position this kind of methodology within the broader qualitative narrative enquiry methodologies (Bruner, 1990), which are based on the exploration of the way people construct and organize their own subjective and emotional experience through narratives.
The research took place at Regional Multiple Sclerosis Center of Federico II University Hospital of Naples and was carried out during the year 2014/2015. The study was conducted according to the Helsinki Declaration and was approved by the Institutional Review Board of the same University.

We decided to contact by phone women patients who met the eligibility criteria reported in table 1 after consulting outpatient clinic’s registers.

Table 1. Eligibility criteria

| MS diagnosis received | > 6 months |
|-----------------------|------------|
| Age                   | between 25 and 40 years; |
| Severity of disability measured by Expanded Disability Status Scale (EDSS) (Kurtzke, 1983) |
|                       | < 3.5 |

These criteria are the outcome of some methodological choices. We decided to involve women interesting in maternity topic, in age range between 24 and 40 (Table 1). The chosen age range reflects the relationship between the average age of onset of MS and the age group during which women more frequently become pregnant or decide to have a child. We also decided to involve subjects who knew their diagnosis for at least six months so as not to interfere with the first phase of the psychological reaction to the diagnosis communication (Mattarozzi et al., 2012). The degree of physical disability has been established to low-grade, the lower than 3.5 on the Expanded Disability Status Scale (1983) (footnote reference), because at this level of progression of disease it does not significantly compromise the autonomy of the subject (Table 1).

Overall, 65 women were contacted. Among these, twenty-eight of them showed an interest in motherhood topic and agreed to participate to the research program. After having met the first twenty subjects, on the basis of the data that had been collected and analyzed, further data collection and/or analysis was established to be unnecessary, showing that saturation was reached.

All women were met at the outpatient clinic of Regional Multiple Sclerosis Center of Federico II University of Naples. All women declared their interest to be enrolled in the project and they agreed to participate afterwards to periodical group sessions specifically focused on maternity experiences.

The first encounter with each participant was conducted face-to-face, in a dedicated room, by a clinical-psychological researcher, with a long experience in health care organizations. In a broader sense, the researcher is active in data generation. After explaining the purpose of the research, women gave their informed consent and were given a socio-biographical and anamnestic information collection form with regard to the following qualitative and quantitative data: age, type of diagnosis, disease duration, expanded disability status scale index, relationship status, presence of overt procreative difficulties, link between motherhood experience and time since diagnosis.

All these data were collected in a database to perform the statistical analysis.

---

1 The Kurtzke Expanded Disability Status Scale (EDSS) is a widely acknowledged method of quantifying disability in Multiple Sclerosis. The EDSS quantifies disability in eight Functional Systems (FS) and allows neurologists to assign a Functional System Score (FSS) in each of these. John F. Kurtzke (1983), the researcher who developed this scale, defines functional systems as follows: pyramidal; cerebellar; brainstem; sensory; bowel and bladder; visual; cerebral; other. Each of these systems is assigned a score according to the severity of its clinical impairment. The global score that results varies from 0 (no disability) to 10 (death due to MS).
Data collection

To each one of twenty participants was then administered an open interview lasting 30 minutes, introduced by a trigger question as a prompt to freely associate around her own actual or imagined experience of maternity. The following trigger questions were asked verbally and were differentiated on the basis of the actual or only desired motherhood experience.

“Can you tell me something about your personal experience of motherhood, about the time of pregnancy, what happened in that time, your phantasies, your fears …?” (in case of actual previous pregnancies, childbirth and motherhood experiences).

“Have you ever thought of having a child? Can you tell me something about your eventual imagined motherhood experience, …?” (in case of absence of previous pregnancies, childbirth and motherhood experiences).

This choice is justified because if, on the one hand, on a conscious level the real experience forces us to differentiate the words to use, on the other, the unconscious aspects of pregnancies, childbirth and motherhood experiences share the two different perspective and allowed us to treat them on the same scale.

The interviews were audio recorded, transcribed verbatim and stored in a digital privacy-protected archive, in order to carry out an analysis of the textual corpus.

Data analysis

In order to explore the women’s overall meaning-bestowal processes to their expectations or their actual experiences, the analysis of the transcribed interviews was performed through T-LAB software (Lancia, 2004).

T-Lab software is a qualitative-quantitative software for text thematic analysis performed through a series of sophisticated techniques (Bolasco, 1993). This software is based on an analysis of the relation between words or lexical unit within the text (occurrence, co-occurrence).

This analysis seemed to be appropriated for our research question, aimed at investigating themes of narratives bringing them back into semantic universes. Moreover T-lab is particularly appropriate for automatic and systematic analysis of texts of large size.

The transcribed material was submitted, first, to a thematic analysis of elementary contexts (e.c.u.). The analysis produces few significant thematic clusters, each of which: consists of a set of elementary contexts (i.e., sentences, paragraphs) characterized by the same patterns of key-words and is described through the lexical units (i.e., words, lemmas) and the variables most characteristic of the units from which it is composed. This allows the reflection on the meaning of individual words, analyzing it within the context in which they are used. The meaning of a word is known only through its relations with the phrasal contexts, that is, through its distribution within portion of text (Greimas, 1983).

The results of the performed analysis organized the textual material within four main thematic groups (clusters) with a different weight percentage of e.c.u belonging to each cluster. Clusters can be also may be considered as “lexical worlds” because they represent meaning contextual fields (Reinert, 1995).

After a cross-checking of researchers, we attributed a label to each cluster. The label is a sentence used to easily identify the semantic area covered by each cluster. The attribution of
label represents the passage of research that goes from identification of the narratives’ contents to the creation of categories of meanings.

**Results**

As shown in Table 2, the collected data showed a homogeneous group with regard to *age, type of diagnosis* (Relapsing-remitting Multiple Sclerosis for everyone), *expanded disability status scale index* and *absence of overt procreative difficulties*.

### Table 2. Participants’ characteristics

|                        | mean | SD  |
|------------------------|------|-----|
| **Age**                | 34.56 yrs | 3.89 yrs |
| **Type of diagnosis**  | relapsing-remitting | other |
| **Disease duration**   | 7.49 yrs | 4.63 yrs |
| **Expanded Disability Status Scale index** | median | range |
| **Relationship status**| yes | no |
| **Procreative difficulties** | yes | no |
| **Link Motherhood Experience/ Time since Diagnosis** | childlessness | pre-diagnosis | post-diagnosis | pregnant |
| **Time since Diagnosis** | 7 (35%) | 6 (30%) | 4 (20%) | 3 (15%) |

On the contrary, participants appeared to be a heterogeneous group with regard to *disease duration*. Therefore, we decided to differentiate three groups (0-3yrs, 3-10yrs, more than 10yrs) with regard to this characteristic to give value to the differences of the course of the pathology. Indeed, third year from the formulation of the diagnosis is commonly used as a cut-off moment that outlines a clear proclamation of the pathology from a medical point of view, and ten years indicate a sufficient period to categorize type of clinical form and course (Confavreux, Aimard, & Devic, 1980). Apart from age of onset of disease, participants were a heterogeneous group with regard to motherhood as well: for this reason we decided to consider four groups (childlessness, pre-diagnosis, post-diagnosis, pregnant) with regard to the characteristic *link motherhood/disease*: 50% of the women had experienced motherhood before or after having been diagnosed with MS, 15% women at the time of the interview were experiencing a primipara pregnancy, the remaining 35% were considering the possibility of, had expressed a desire for, or were planning motherhood.

Finally, the characteristic *relationship status*, through two modalities (yes, no), informed us that most of the participants had a stable partner (80%).

**Cluster Analysis**

From the cluster analysis, four core themes emerged: *Family Role* (Cluster 4); *Daily Pain* (Cluster 2); *Relationship with Health Care Services* (Cluster 1) and *Closing the Circle* (Cluster 3).
Table 3. Description of cluster

| Cluster                     | Lemma that mainly characterize the cluster based on the value of χ² |
|-----------------------------|---------------------------------------------------------------|
| Family role                 | partner (5.82), mother (5.69), living (5.66), boy (4.88), son (4.84), baby (4.21), person (4.12) |
| Daily Pain                  | bed (9.443), eating (9.19), pain (9.05), reading (8.97), walking (8.01), kilo (7.97), eye (7.26), succeeding (6.31), falling asleep (6.17), waking up (6.17), leg (6.06), sleeping (6.01), cooking (5.44), moving (5.04), strolling (5.04), muscle (4.60), relaxing (4.60), sitting (4.60), cervical (4.12), body (4.12), uncomfortable (4.12), sofa (4.12), stupid (4.12) |
| Relationship with Health Care services | drug (12.67), suspending (10.23), patient (8.90), controls (7.77), professor (7.53), resonance (7.51), therapy (7.27), beginning (7.14), effect (7.12), information (6.37), center (5.82), rebound (5.39), decided (5.39), starting (4.96), non-profit organizations (4.82), hospitalizing (4.82), associations (4.58) |
| Closing the circle          | closed (14.6), circle (14.58), sensation (12.86), closing (11.90), suffering (10.87), being worth (10.87), placing (9.72), precise (9.72), winning (9.72), trying (9.53), choice (7.18), testimony (7.11), personal (6.58), waiting (5.43), end (4.65), idea (4.15), discourse (4.07), goal (4.07) |

Table 3 indicates the characteristics of each cluster, i.e., the lexical units that make it up and the relative values of χ². The lemmas that make up the cluster are sorted in descending order considering their χ² weight starting from the cluster which is statistically more significant (p = .05).

Cluster 4—*Family Role*—brings out the theme of motherhood in the broader sense of the idea of family as relational and social structure. In this cluster we can find lemmas like “partner,” “mother,” “son.” All lemmas within this cluster refer to familiar relationships which are valued for their capacity of protecting the personal characteristics of its members. The statistical weight of this cluster, which is the most significant, seems to indicate an extensive cultural sharing between subjects of this kind of motherhood meaning-frame. Within this cluster, the variables "Pregnant" and "knowledge of the disease for over 10 years" are highly represented. The following extract associated with this cluster shows how the child herself seems to play an active and protective role for her mother in a sort of reversing-role:

> During pregnancy you feel good, it seems more that your child is protecting you and not that you are protecting your child. Now, then, if I had not had problems with my sciatic nerve ... but it was not for multiple sclerosis, no, doctors have excluded it with certainty [Pregnant] (21.849)

In Cluster 2—*Daily Pain*—there are lemmas that describe the difficulties subjects are forced to confront with by virtue of the disease condition (pain; uncomfortable); the reference is to concrete aspects (kilo; leg; muscle; cervical) and daily activities (eating; walking). All these references are bundled up into a representation of the limits imposed by the disease to the subject. Within this cluster the variable "no couple relationship" is highly represented. The following is an extract:

> It is like a baggage you must always carry on your shoulders, it is a baggage, day by day it is always a weight [without a significant couple relationship] (18.027)
The Cluster 1—*Relationship with Health Care Services*—is composed of lemmas which are referred to feelings of loss of autonomy and to an ambivalent reliance, desired (and feared) trusting, feelings of control and dependence on the health care services for keeping an adequate quality of life (drug; patient; professor; rebound). What emerges within this cluster is a sort of shrinking of personal identity to the *role of patient*; the disease and consequent medical procedures manifest themselves as a totalizing and overwhelming situation. The disease appears as a condition that may dramatically compromise the quality of life and make it harder. Some significant variables fall into this cluster, such as “knowledge of being affected by the disease for a shorter time” and motherhood before the onset of the disease (pre-diagnosis time). For example, one of the interviewed women had this to say:

> Before being diagnosed I wanted to have a child but I had to wait two years, then the doctor gave me the ok. After giving birth I wanted to replace the drug in order to be 100% for the little girl, maybe that's why I had the relapse [post-diagnosis motherhood] (21.035)

In Cluster 3—*Closing the Circle*—we can find lemmas that share the reference to the desire for motherhood as a life goal to be pursued (closed; circle; winning; goal) in terms of personal choice (choice; testimony). The covered semantic area refers to the reacquisition of personal value, the revalorization of one’s own abilities and the possibility of redemption at the end of a path full of difficulties. It is noteworthy that within this cluster we find the variable “knowledge of presence of disease for a fair time.” One of the extracts within this cluster is the following:

> However, having a child means that a circle is closing, it heartens you, it's like you won something for yourself, not for your husband, it is an intimate thing, personal, it means achieving a goal, that’s how I see it [post-diagnosis motherhood] (3.509)

**Interpretation of the Clusters on the Factorial Plane**

Through the projection of the clusters on the factorial plane it is possible to observe and interpret the relationships between the different threads that emerge and understand the factors that link them (see Figure 1). This figure considers the clusters factorial projection on the axes.

- Clusters: 1= Relationship with Health Care Services; 2=Daily pain; 3=Closing the circle; 4=Family role.
- Active variables:
  - a) CR_no (Couple Relationship): no partner at the time of interview.
  - b) ME/D (Motherhood Experience/Disease, the link between motherhood experience and time since diagnosis): 1=childlessness; 2=Pre-diagnosis motherhood; 3=Post-diagnosis motherhood; 4=pregnant.
  - c) TD (Time of Diagnosis, time since the moment of knowledge of disease diagnosis): 1=from six months to three years; 2=from three to ten years; 3=over ten years.
- Three vectors of meaning:
  - ✓ Factor I “From Concrete to Abstract”;
  - ✓ Factor II “From Life-Project to Relapse”;
  - ✓ Factor III “From Health Agencies to Family Support.”
Considering the clusters factorial projection on the axes, we identified three meaning vectors that have guided our interpretation of the subjects’ narrative themes within their discourses, i.e., of their world-project (Holzhey-Kunz, 2014; Margherita & Gargiulo, 2018; Martino et al., 2019; Vitelli, 2018): From Concrete to Abstract (factor I); From Life-Project to Relapse (factor II), From Health Agencies to Family Support (factor III).

The first horizontal axis - From Concrete to Abstract – represents a continuum that ranges from a polarity of the factorial plan (left quadrants), in which concrete aspects of the disease, with dependence on the medical system and relationships within the context of associations as well as general difficulty, emerge (Cluster Relationship with Health Care Services and Cluster Daily Pain), to another polarity (right quadrants) in which the reference is to more abstract dimensions and idealized family and motherhood representation (Cluster Family Role and Cluster Closing the Circle).

On the second vertical axis, that we have named From The Life-Project To Relapse, we can find a continuum that goes from the lower polarity of the factorial plane in which maternity is inscribed within contextual constraints (Cluster Relationship with Health Care Services) or is an expression of a desire for self-sufficient empowerment (Cluster Closing the Circle), to the higher polarity in which the changes involve the paralyzing risk of daily pain (Cluster 2) or a retreat into a space which might compensate for possible deficiencies (Cluster Family Role). In this case it seems that a sense of “mortification” is derived from the personal restraint related to the patient role, the dependency on the Health System, and the impact of disease upon one's own life, but, at the same time, subjects seem to try to retrieve different social roles and existential possibilities.

On the third diagonal axis, the third factor from Health Agencies Support to Family Support, manifests itself as a dialectic instance where the Relationship with Health Care Services Cluster is opposed to the Family Role Cluster. This axis refers to the attempt of holding together maternity and disease through the relational contexts, to the family as a private and intimate existential dimension.
Discussion

Personal experience in women living with MS seems to be characterized by an overall difficulty in combining aspects related to the medical/therapeutic pathways and personal life projects, that is, to the chronicity of the disease and the life-projectuality and motherhood-projectuality.

Considering the results of our research, if on the one hand the patient role brings out in the foreground the representation of the context of the Health Agencies and the disability distress, on the other, the mother role seems to refer to an idealized model, independently achievable and free from the background of MS. Referring to the identity dimensions, some difficulty emerges within the positively valuing processes of one’s own functions and abilities, but, at the same time, pregnancy seems to have a positive effect on self-esteem. The medical context is perceived both as protective and restraining. One’s own personal identity stabilizing processes seem to pass through the centrality of the body, the pain, the symptoms that stain one’s own being-in-the-world, that is, one’s own life-experiences. At the same time, the role of mother and woman within the couple relationship is configured as a chance for “redemption” for the existential “injustice” inflicted by disease.

For the women we interviewed, pregnancy appears as a protective condition and motherhood representation is referred to family roles which are considered far from the medical care context and important for their own self-esteem. At the same time, as already previously reported in the scientific literature (Pakenham & Flemming, 2011), the presence of a stable couple relationship appears to be a very important protective factor, because it helps women to bear the difficulty with which they have to coexist daily and, in particular, with the limits that the disease often imposes.

Knowing diagnosis for more than ten years is generally accompanied by a mobilization of relational and vital resources for one’s own generative desire. In this sense, the long-term disease seems to determine a better adaptation and a strengthen of coexistence capacity with the unpredictability of MS (Laplaud & Confavreux, 2006; Rainone et al., 2017).

On the contrary, maternity projects seem to be less “independent” and more “risky” for women who have known about the presence of disease for a shorter time: in this case, subjects seem to manifest a greater dependence from medical and major concerns for their physical health.

Conclusions

The results of our research show that motherhood cannot be considered apart from the interweaving of several features that characterize the complexity of Multiple Sclerosis: the typical unforeseeable course of the disease as well as the uniqueness of each individual clinical case. From a medical point of view, motherhood may be considered for the patient as a possible “risk” or as a possible “protective” factor, i.e., as an event that can produce an improvement in her overall well-being.

In any case, just because Multiple Sclerosis cannot be considered only a somatic disease but at the same time a manifold existential condition, it is only through the possibility of an interdisciplinary dialogue—medical and psychological—and within the subjects’ global existential meaning-bestowing, that the eventuality of pregnancy/motherhood can be fully and really re-thought.

This contribution offers a brief reflection on the importance of the specific way women suffering from Multiple Sclerosis give meaning to the experience of pregnancy and motherhood. In particular, it invites clinicians to consider this eventuality to better understand needs and priority for women with MS (Carlino, 2015; Carlino, Di Toppa, Policelli, Chiodi,
A perspective based on qualitative research in multiple sclerosis focused on “patients' voices” (Glässel et al., 2019) is important for medical and health professionals to reflect on the inner experiences of illness and to support women and their families along so important changes in life such as pregnancy and motherhood (Margherita, Gargiulo, & Caffieri, in press).

Limitations and Future Directions

The current study is not free from limitations. Women who were enrolled in the research program are a heterogeneous group with regard to the (actual or only imagined) motherhood experience. So, the first limitation of this study is the limited number of involved subjects: in the future the size of the sample should be increased for the possibility of obtaining a more homogeneous group of women with regard to the experience of maternity. Moreover, future research should be extended to the exploration of representational dimensions within the family members and medical practitioners as well: after all, pregnancy is not only a private affair, but also a social and interpersonal event. Meanings themselves are not properly only to be referred to the singular subject but must be always thought within the life-world as derived and re-shaped off a wider common shared-world-horizon.

Pregnancy as life-project cannot be considered a solipsistic choice: father and other parents and caretakers have to be taken into account as well to a much larger degree than until now has been previously done.

References

Alwan, S., Yee, I. M., Dybalski, M., Guimond, C., Dwosh, E., Greenwood, T. M., Butler, R., & Sadovnick, A. D. (2012). Reproductive decision making after the diagnosis of multiple sclerosis (MS). *Multiple Sclerosis Journal, 19*(3), 351-358. http://dx.doi.org/10.1177/1352458512452920

Ammaniti, M., Tambelli, R., & Odorisio, F. (2013). Exploring maternal representations during pregnancy in normal and at risk samples: The use of the interview of maternal representations during pregnancy. *Infant Mental Health Journal, 34*(1), 1-10. http://dx.doi.org/10.1002/imhj.21357

Bibring, G. L., Dwyer, T. F., Huntington, D. S., & Valenstein, A. F. (1961). A study of the psychological processes in pregnancy and of the earliest mother-child relationship. *The Psychoanalytic Study of the Child, 16*(1), 9-24. https://doi.org/10.1080/00797308.1961.11823197

Birk, K. A., & Kalb, R. (1992). MS & planning a family: Fertility, pregnancy, childbirth and parenting roles. In R. Kalb, & L. Scheinberg (Eds.), *Multiple sclerosis and the family* (pp. 51-62). New York, NY: Demos.

Bolasco, S. (1993). Choix de lemmatisation en vue des reconstructions syntagmatiques du texte par l’analyse des correspondances [Choice of lematization in view of the syntagmatic reconstructions of the text by the correspondence analysis]. In *Actes des Secondes Journées Internationales d’Analyse Statistique de Données Textuelles [Proceedings of the Second International Day of Statistical Analysis of Textual Data]* (pp. 399-410). Montpellier, France: JADT.

Bornemark, J., & Smith, N. (Eds.). (2016). *Phenomenology of pregnancy*. Stockholm, Sweden: Södertörn Philosophical Studies.

Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.

Carlino, M. (2015). SIM. Scelgo Io la Maternità. Ricerca-intervento sugli aspetti psicologici
della maternità di donne con diagnosi di Sclerosi Multipla in un servizio ospedaliero [SIM. It’s up to me the maternity choice. A research-intervention about the psychological aspects of the motherhood of women with a Multiple Sclerosis diagnosis in a health care service] (Tesi di Dottorato) (Doctoral Thesis). Università degli Studi di Napoli Federico II [University of Studies of Naples Federico II]. Retrieved from http://www.fedoa.unina.it/

Carlino, M., Di Toppa, U., Policelli, S., Chiodi, A., & Margherita, G. (2015). Psychological function in the relationship between hospital and community: A research intervention about Multiple Sclerosis and generativity. Rivista di Psicologia Clinica [Clinical Psychology Journal], (2), 44-60. http://dx.doi.org/10.14645/RPC.2015.2.549

Carlino, M. & Margherita, G. (2016). La maternità in donne con Sclerosi Multipla. Una ricerca esplorativa sulle possibili dimensioni di benessere nella malattia [Motherhood in women with Multiple Sclerosis. An explorative research about the possible dimensions of well-being even in the illness]. Psicologia della salute [Health Psychology], 3, 5-25. http://dx.doi.org/10.3280/PDS2016-003001

Cavalla, P., Rovei, V., Masera, S., Vercellino, M., Massobrio, M., Mutani, R., & Revelli, A. (2006). Fertility in patients with multiple sclerosis: Current knowledge and future perspectives. Neurological Sciences, 27(4), 231-239. http://dx.doi.org/10.1007/s10072-006-0676-x

Confavreux, C., Aimard, G., & Devic, M. (1980). Course and prognosis of multiple sclerosis assessed by the computerized data processing of 349 patients. Brain: A Journal of Neurology, 103(2), 281-300. https://doi.org/10.1093/brain/103.2.281

Ferraro, F., & Nunziante Cesàro, A. (1985). Lo spazio cavo e il corpo saturato. La gravidanza come “agire” tra fusione e separazione [The hollow space and the saturated body. The pregnancy as ‘acting’ between fusion and separation]. Milano, Italy: Franco Angeli.

Finkelsztejn, A., Brooks, J. B. B., Paschoal, F. M., & Fragoso, Y. D. (2011). What can we really tell women with multiple sclerosis regarding pregnancy? A systematic review and meta-analysis of the literature. BJOG: An International Journal of Obstetrics & Gynaecology, 118(7), 790-797. http://dx.doi.org/10.1111/j.1471-0528.2011.02931.x

Glässel, A., Streeck, N., Mouton Dorey, C., Briegel, D., Spitale, G., Kesselring, J. & Biller-Andorno, N. (2019). Talking about life with Multiple Sclerosis: A qualitative study of patient experiences. In 21st State of the Art Symposium, “Challenges in MS Treatment and Research,” Lucerne, 26 January 2019 (p. 23). Swiss Multiple Sclerosis Society.

Greimas, A. J. (1983). About the sense. Milano, Italy: Bompiani.

Grue, L., & Lærum, K. T. (2002). Doing motherhood: Some experiences of mothers with physical disabilities. Disability & Society, 17(6), 671-683. http://dx.doi.org/10.1080/0968759022000010443

Hellwig, K., & Correale, J. (2013). Artificial reproductive techniques in multiple sclerosis. Clinical Immunology, 149(2), 219-224. http://dx.doi.org/10.1159/000367640

Holzhey-Kunz, A. (2014). Daseinsanalyse [Analysis of existence] (S. Leighton, Trans.). London, UK: Free Association Books.

Houvouras, S. (2006). Negotiated boundaries: Conceptual locations of pregnancy and childbirth. The Qualitative Report, 11(4), 665-686. http://www.nova.edu/ssss/QR/QR11-4/houvouras.pdf

Kurtzke, J. F. (1983). Rating neurologic impairment in multiple sclerosis an expanded disability status scale (EDSS). Neurology, 33(11), 1444-1444. http://dx.doi.org/10.1212/WNL.33.11.1444

Lancia, F. (2004). Strumenti per l’analisi dei testi. Introduzione all’uso di T-LAB [Tools for text analysis. Introduction to use T-Lab]. Milano, Italy: Franco Angeli.

Langer-Gould, A. & Beaber, B. E. (2013). Effects of pregnancy and breastfeeding on the
multiple sclerosis disease course. Clinical Immunology, 149(2), 244-250. http://dx.doi.org/10.1016/j.clim.2013.01.008

Laplaud, D. A. & Confavreux, C. (2006). Etiology of multiple sclerosis. La Revue du Praticien, 56(12), 1306-1312.

Lavorgna, L., Esposito, S., Lanzillo, R., Sparaco, M., Ippolito, D., Coco, E., ... Bonavita, S. (2019). Factors interfering with parenthood decision-making in an Italian sample of people with multiple sclerosis: An exploratory online survey. Journal of Neurology, 266(3), 707-716. https://doi.org/10.1007/s00415-019-09193-4

Margherita, G., Boursier, V., Gargiulo, A., & Nicolò, G. (2017). Sognare e narrare la maternità: Un’analisi tematica dei sogni delle gestanti [To dream and to narrate motherhood: a thematic analysis of pregnant women’s dreams]. Psicologia Clinica dello Sviluppo, 21(2), 237–255. http://dx.doi.org/10.1449/87536

Martino, M. L., Picione, R. D. L., Lemmo, D., & Freda, M. F. (2019). Meaning-making trajectories of resilience in narratives of adolescents with MS. Mediterranean Journal of Clinical Psychology, 7(2). http://dx.doi.org/10.6092/2282-1619/2019.7.2049

Mattarozzi, K., Vignatelli, L., Baldin, E., Lugaressi, A., Pietrolongo, E., Tola, M. R., ... G.E.Ro.N.I.Mu.S. (2012). Effect of the disclosure of MS diagnosis on anxiety, mood and quality of life of patients: a prospective study. International journal of clinical practice, 66(5), 504-514. doi: 10.1111/j.1742-1241.2012.02912.x.

Oksenberg, J. R., Baranzini, S. E., Barcellos, L. F., & Hauser, S. L. (2001). Multiple sclerosis: Genomic rewards. Journal of Neuroimmunology, 113(2), 171-184. http://dx.doi.org/10.1016/S0165-5728(00)00444-6

Pakenham, K. I., & Fleming, M. (2011). Relations between acceptance of multiple sclerosis and positive and negative adjustments. Psychology & Health, 26(10), 1292-1309. http://dx.doi.org/10.1080/08870446.2010.517838

Payne, D., & McPherson, K. M. (2010). Becoming mothers. Multiple sclerosis and motherhood: A qualitative study. Disability and Rehabilitation, 32(8), 629-638. http://dx.doi.org/10.3109/09638280903204708
Prunty, M., Sharpe, L., Butow, P., & Fulcher, G. (2008). The motherhood choice: Themes arising in the decision-making process for women with multiple sclerosis. *Multiple Sclerosis*, 14(5), 701-704. [http://dx.doi.org/10.1177/1352458507086103](http://dx.doi.org/10.1177/1352458507086103).

Rainone, N., Chiodi, A., Lanzillo, R., Magri, V., Napolitano, A., Morra, V. B., ... Freda, M. F. (2017). Affective disorders and health-related quality of life (HRQoL) in adolescents and young adults with multiple sclerosis (MS): The moderating role of resilience. *Quality of Life Research*, 26(3), 727-736. [https://doi.org/10.1007/s11136-016-1466-4](https://doi.org/10.1007/s11136-016-1466-4).

Reinert, M. (1995). I mondilessicali di un corpus di 304 racconti di incubi attraverso il metodo Alceste [Lexical worlds of a corpus of 304 tales of nightmares through Alceste method] In R. Cipriani, & S. Bolasco (Eds), *Ricerca qualitativa e computer* [Qualitative research and computer] (pp. 203–223). Milan, Italy: Franco Angeli.

Soifer, R. (1985). *Psicologia da gravidez, parto e puerpério* [Psychology of the pregnancy, delivery and postpartum] Porto Alegre, Brazil: Artes Médicas.

Stern, D. N. (1995). *The motherhood constellation: A unified view of parent-infant psychotherapy*. New York, NY, USA: Basic books.

Tessitore, F. & Margherita, G. (2019). Female Nigerian asylum seekers in Italy: An exploration of gender identity dimensions through an interpretative phenomenological analysis. *Health Care for Women International*. [https://doi.org/10.1080/07399332.2019.1692849](https://doi.org/10.1080/07399332.2019.1692849).

Trojano, M., Lucchese, G., Graziano, G., Taylor, B. V., Simpson, S., Jr., Lepore, V. & Amato, M. P. (2012). Geographical variations in sex ratio trends over time in multiple sclerosis. *PLoS One*, 7(10). [https://doi.org/10.1371/journal.pone.0048078](https://doi.org/10.1371/journal.pone.0048078).

Vitelli, R. (2018). Binswanger, Daseinsanalyse and the issue of the Unconscious: An historical reconstruction and a rethinking of Daseinsanalytic Psychotherapy. *Journal of Phenomenological Psychology*, 49(1) 1-42. [http://dx.doi.org/10.1163/15691624-12341343](http://dx.doi.org/10.1163/15691624-12341343).

Weinshenker, B. G., Bass, B., Rice, G. P., Noseworthy, J., Carriere, W., Baskerville, J., & Ebers, G. C. (1989). The natural history of multiple sclerosis: a geographically based study. I. Clinical course and disability. *Brain*, 112(Pt 1), 133-46. [https://doi.org/10.1093/brain/112.1.133](https://doi.org/10.1093/brain/112.1.133).

**Author Note**

Maria Carlino is Psychologist, Psychotherapist and PhD. Now she works as a Military Psychologist. After graduation in Dynamic, Clinic and Community Psychology and her PhD in Gender Studies at Department of Humanistic Studies (University of Naples Federico II), she specializes in Psychoanalytic Psychotherapy. She deals with the interconnections between gender issues and psychological aspects of physical illness from a dynamic psychological perspective. Correspondence regarding this article can be addressed directly to: mariacarlino@alice.it.

Roberta Lanzillo is researcher in Neurology at the Multiple Sclerosis Centre of Federico II University. Her main interest is clinical and therapeutic research, in particular, pediatric MS and sexual dysfunctions in people with MS. She has developed, in cooperation with the division of Clinical Psychology, educational instruments to facilitate communication with young people with MS and sexuality and pregnancy issues for adults. She is member of the Italian Neurological Society (SIN) and of MS, Digital, and Gender Medicine SIN study groups. Correspondence regarding this article can also be addressed directly to: robertalanziol@libero.it.

Alessandro Chiodi is Clinical Psychologist, Psychodynamic Psychotherapist, Coordinator of Psychology Group for MS, University Hospital of Naples Federico II, Head-
Neck Integrated Activity Department, Complex Operative Unit of Psychiatry and Psychology. Correspondence regarding this article can also be addressed directly to: alessandro.chiodi@unina.it.

Roberto Vitelli is Assistant Professor in Clinical Psychology at the Federico II University of Naples. He is co-founder of the Gender Dysphoria Psychological Service, run since 1997 by the Federico II University Hospital. In his current work he is investigating Gender Variance by integrating philosophical and psychological resources. He is a member and co-founder of the School for Psychotherapy and Phenomenological Clinical Work – Florence (Italy). Correspondence regarding this article can also be addressed directly to: rvitelli@unina.it.

Luigi Lavorgna is a Neurologist of University of Campania “Luigi Vanvitelli.” He founded, in 2012, the first social network entirely dedicated to Multiple Sclerosis. He works on social determinants of neurological diseases and is an author of scientific articles on multiple sclerosis and social media/digital technologies. Correspondence regarding this article can also be addressed directly to: Luigi.Lavorgna@policliniconapoli.it.

Vincenzo Brescia Morra is assistant professor in Neurology and Director of the Multiple Sclerosis Centre of Federico II University. His main interest is clinical and therapeutic research in MS and development of health care guidelines and cost effectiveness studies in MS. He is a member of the Italian Neurological Society (SIN) and of MS study group.

Giorgia Margherita is Researcher in Psychodynamic Psychology, she teaches Dynamic Psychology at University of Naples Federico II and is Member of the College of the PhD in Mind Gender and Language. She is also Psychologist and Psychotherapist, so as Group Psychoanalyst Member of (I.I.P.G.) Italian Institute of Psychoanalysis Group. She is also member of (E.F.P.P.) European Federation for Psychoanalytic Psychotherapy in the Public Sector. Correspondence regarding this article can also be addressed directly to: margheri@unina.it.

Copyright 2020: Maria Carlino, Roberta Lanzillo, Alessandro Chiodi, Roberto Vitelli, Luigi Lavorgna, Vincenzo Brescia Morra, Giorgia Margherita, and Nova Southeastern University.

Article Citation

Carlino, M., Lanzillo, R., Chiodi, A., Vitelli, R., Lavorgna, L., Morra, V. B., & Margherita, G. (2020). Multiple sclerosis and maternity: A psychological explorative qualitative research. The Qualitative Report, 25(5), 1279-1292. https://nsuworks.nova.edu/tqr/vol25/iss5/8