Journal of Neurology (2019) 266:707–716
https://doi.org/10.1007/s00415-019-09193-4

ORIGINAL COMMUNICATION

Factors interfering with parenthood decision-making in an Italian sample of people with multiple sclerosis: an exploratory online survey

L. Lavorgna[1] · S. Esposito[1,2] · R. Lanzillo[3] · M. Sparaco[1] · D. Ippolito[1] · E. Cocco[4] · G. Fenu[4] · G. Borriello[5] · S. De Mercanti[6] · J. Frau[4] · R. Capuano[1] · F. Trojsi[1] · L. Rosa[3] · M. Clerico[6] · A. Laroni[7] · V. Brescia Morra[3] · G. Tedeschi[1,8] · S. Bonavita[1,8]

Received: 29 July 2018 / Revised: 21 December 2018 / Accepted: 8 January 2019 / Published online: 16 January 2019

Abstract

Background Little is known about the influence of multiple sclerosis (MS) diagnosis on parenthood attitude in people with MS (pwMS).

Objective To investigate the impact of diagnosis, clinical features and external disease-related influences on parenthood decision-making in Italian pwMS.

Methods A web-based survey was posted on SMsocialnetwork.com to investigate clinical status, parenthood desire, influences on family planning, pregnancy outcomes, abortions and adoptions of pwMS.

Results 33/395 respondents never wanted to become parent because of MS ("anti-parenthood after diagnosis"). 362 declared to be in favor of parenthood. 51% pwMS having a child by the survey time had already received the MS diagnosis at first childbirth. The frequency of a second child in pwMS after diagnosis was 38% compared to 67% in people without yet MS diagnosis. 16% of pwMS were discouraged to become parent after diagnosis, mainly by medical personnel. In 71% of respondents, diagnosis did not delay the decision to become parent and only 39% were counseled by treating physician to plan pregnancy. Patients' distribution according to the clinical phenotype (exclusively relapsing vs exclusively progressive) showed a higher proportion of progressive patients in the "anti-parenthood after diagnosis" subgroup.

Conclusion MS diagnosis impacted dramatically on the life project of 7% of pwMS that decided not to have children because of the disease and in pro-parenthood pwMS impacted especially on having the second child. Only a minority was counseled to plan pregnancy. A worse disease course driving to a progressive phenotype at survey time might have negatively impacted on parenthood desire.

Keywords Multiple sclerosis · Parenthood · e-health · Online survey

L. Lavorgna and S. Esposito contributed equally to the manuscript.

Electronic supplementary material The online version of this article (https://doi.org/10.1007/s00415-019-09193-4) contains supplementary material, which is available to authorized users.

✉ L. Lavorgna
luigi.lavorgna@policliniconapoli.it

1 First Division of Neurology, University of Campania Luigi Vanvitelli, Piazza Miraglia, 2, 80138 Naples, Italy

2 Department of Neuroscience, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy

3 Department of Neurosciences, Reproductive Sciences and Odontostomatology, University Federico II, Naples, Italy

4 Department of Medical Sciences and Public Health, Multiple Sclerosis Centre, Binaghi Hospital, University of Cagliari, Cagliari, Italy

5 Department of Neurology and Psychiatry, S. Andrea MS Center, Sapienza University, Rome, Italy

6 Clinical and Biological Sciences Department, University of Torino, Turin, Italy

7 Department of Neuroscience, Rehabilitation, Ophthalmology, Genetics, Maternal and Child Health, IRCCS AOU San Martino-IST, University of Genoa, Genoa, Italy

8 Neurological Institute for Diagnosis and Care "Hermitage Capodimonte", MRI Center SUN-FISM, Naples, Italy

Introduction

Multiple sclerosis (MS) is the second leading cause of neurological disability in young adults, with a female prevalence and a disease onset in the reproductive age [1]. The new diagnostic criteria allowed the anticipation of diagnosis usually occurring in childbearing years [2]. After being diagnosed, people with MS (pwMS) must deal with the "disease representation", characterized by sudden onset, unpredictable course, disabling symptoms and uncertain prognosis, facing significant challenges regarding psychological adjustment and acceptance [3]. Accordingly, recently diagnosed pwMS and their partners frequently show a worsening quality of life with high levels of anxiety and distress [4, 5]. The emotional discomfort may negatively impact on their decision-making process [6] affecting life decisions and family planning. Growing evidence on the neutral/positive effect of pregnancy on MS, and the better knowledge on disease-modifying treatment (DMT) safety, has led to an overall risk minimization through both a better definition of drugs' cost–benefit profile [7] and the counseling process to plan pregnancy and breastfeeding [8, 9]. However, for pwMS, family planning may raise worries about the effects of pregnancy on disease course, about the heredity of MS, and about fetal or pediatric safety related to DMT assumption at the time of conception, during pregnancy and breastfeeding. Although the advances on knowledge about the reciprocal effect of pregnancy and MS might have contributed to encourage pwMS on family planning, the frequency of childlessness in pwMS is higher than in the general population and the association between nulliparity and MS tends to increase with age [10]. A large study, focused on reproductive attitudes and behavior of North American pwMS, highlighted some deep-seated concerns such as inadequate parenting abilities, passing on MS to the child and possible risks associated with exposure to medications during pregnancy [11]. A recent study, reporting the results of an online survey investigating pwMS awareness about family planning, showed that the 30% of respondents did not have children and that, among these, the 50% wanted to start a family, with no significant difference between respondents with high disease activity being less likely to want to start a family than respondents with lower disease activity [12]. To our knowledge, little is known about the putative influence of diagnosis and disease status processing on parenthood desire and realization in Italian pwMS.

Objective

To better understand the factors influencing Italian pwMS' family planning process we designed a web-survey investigating (1) the impact of diagnosis, clinical features and external disease-related influences on parenthood decision-making and (2) the mismatch between this desire and the effective children birth.

Methods

Web-based survey and SMsocialnetwork

We posted on the public wall of SMsocialnetwork.com a web-based 26-item survey, created with the collaboration of a group of neurologists and psychologists of the First Clinic of Neurology of the University of Campania "Luigi Vanvitelli", with expertise in MS and web. The five main interest areas of the survey were (1) social and clinical status, (2) parenthood desire, (3) external influences during the elaboration phase of family desire, (4) pregnancy outcomes and (5) abortions and adoptions.

The survey was posted from November to December 2016 on the public wall of http://www.SMsocialnetwork.com, a Facebook-like social network completely dedicated to pwMS and supervised by a team of neurologists and psychologists [13]. The survey was displayed in a popup window when visitors accessed to the website (the full Italian version is available in Supplemental Material). To gauge the recruitment bias via online survey, we compared the main characteristics (age, M/F ratio) of respondents to the corresponding data from the "Barometro 2018" (https://www.aism.it/index.aspx?codpage=2018_barometro_sclerosi_multipla) from the Italian Association of Multiple Sclerosis (AISM) which gives a snapshot on multiple sclerosis in Italy in 2017; furthermore, regarding age at first child birth of women with MS we compared the age at first child birth of our sample with the mean age at first child birth of the general population of Italian women from ISTAT (Italian Public Institute of Statistics) (https://www.istat.it/it/files//2011/10/testointegrale200807011.pdf).

Registration, pwMS consent and privacy policy

The study was performed in accordance with good clinical practice and the Declaration of Helsinki. All participants consented to the use of recorded surveys for scientific purposes on aggregate level. To protect the anonymity of the participants, the Internet protocol codes of the computers were not registered, and no electronic "cookies" were embedded.

We followed the directive 95/46/ec of the European Parliament and of the Council of October 24, 1995, on the protection of individuals regarding the processing and free transfer of personal data (https://eur-lex.europa.eu/legal-content).

Statistical analysis

All pwMS' answers, anonymously transferred to an electronic database, were analyzed using the STATA version 14.1 software package (StataCorp, College Station, Texas, http://www.stata.com). Continuous variables were described as relative frequencies, medians or means and standard deviations (SD). The Chi-square test, or when necessary the Fisher's exact test, was used for testing correlation among the categorical variables. Student's *t* test and one-way analysis of variance (ANOVA) were used to compare parametric data, respectively, between two or among more groups. The Bonferroni correction was applied to any post hoc comparison of frequencies or averages. A *p* value lower than 0.05 was considered statistically significant.

Results

We collected 519 surveys and considered 484 of them, excluding

- 35 for missing data (surveys with > 20% of missing answers) [14].

Of note, not being mandatory to answer to each item, the number of respondents to each item might vary.

The study sample consisted of 345/484 (71%) of women with a mean (SD) age of 40.8 (10.5) years at the time of the survey. 462/484 (95%) answered to the item investigating the years of education; among these 407/462 (88%) were predominantly highly educated with at least 13 years of education. The mean (SD) age at MS onset and diagnosis were, respectively, 27.7 (8.9) and 30.7 (9.5) years.

When comparing our sample to the MS population reported by the "Barometro 2018", respondents had a mean age of 40.8 vs 46 years of the "Barometro" pwMS; F/M ratio was 2.7 in our population vs 2.3 in the "Barometro" one.

377/484 (78%) answered to the item investigating the presence of relapses and 286/377 (75%) stated to have a relapsing MS phenotype. 373/484 (77%) answered to the item investigating about the presence of progression and 151/373 (40%) confirmed to have progression. The two answers about relapses and progression were not mutually exclusive.

474/484 (98%) answered to the item investigating the walking ability and 284/474 (60%) declared to walk more than 500 m without assistance or resting.

462/484 (95%) answered to the item investigating therapies with DMTs at the time of the survey, and 231/462 (50%) of pwMS were, according to the Italian Pharmaceutical Agency (Agenzia Italiana del farmaco, AIFA, https://www.agenziafarmaco.gov.it), in first-line DMTs, 141/462 (30.5%) in second-line DMTs and 90/462 (19.5%) were therapy free or in other therapies (see Table 1).

Patient stratification

Analyzing the answers to the critical 13th item of the survey (Q13: "How old were you when you decided to become parent?"), we performed a sample stratification according to the desire to become parent ("pro-parenthood").

122/484 (25%) of respondents declared not to desire to become parent ("anti-parenthood").

89/122 (73%) declared not to desire to become parent for not-MS-related reasons ("anti-parenthood for their own reasons") and 33/122 (27%) never wanted to become parent because of MS ("anti-parenthood after diagnosis"). The subgroup "anti-parenthood for their own reasons" was excluded from any further analyses because it was not contributory to the aim of our study. Therefore, our sample consisted of 395 pwMS.

Pro-parenthood subgroups

The "pro-parenthood" had a mean age of 41.7 (SD 9.2) years at the survey time.

362/395 (92%) declared to be in favor of parenthood ("pro-parenthood"). Of them, 358/362 (99%) answered to the item "have you been diagnosed with MS when you decided to become a parent?" while 4 pwMS gave no answer to this item.

Among these 358 pwMS, 167/358 (47%) had already received the diagnosis of MS at decision time ("pro-parenthood after diagnosis") while 191/358 (53%) were still unaware of the upcoming disease ("pro-parenthood before diagnosis") (see Fig. 1).

343/358 (96%) "pro-parenthood" answered to the item "by the time of this survey, do you have a child?" and, among these, 291/343 (84%) answered positively, while

Table 1 Demographic and clinical characteristics of the survey sample

Sex: F (*n*, %)	345/484 (71%)
Age (M, SD)	40.8 ± 10.5
≥ 13 years of education (*n*, %)	407/462 (88%)
Age at onset (M, SD)	27.7 ± 8.9
Age at diagnosis (M, SD)	30.7 ± 9.5
Relapsing MS phenotype (*n*, %)	286/377 (75)
Signs of progression (*n*, %)	151/373 (40)
Maximum walk distance > 500 m (*n*, %)	284/474 (60)
First-line DMT (*n*, %)	231/462 (50)
Second-line DMT (*n*, %)	141/462 (30.5%)
Not in therapy	90/462 (19.5%)

DMT disease-modifying treatment

52/343 (16%) gave a negative answer. Among these 291 pwMS having a child by the survey time, 286 answered to the item "Had you been already diagnosed with MS at the time of first child birth?" and 5 pwMS did not respond; 147/286 (51%) had already received the MS diagnosis while 139/286 (49%) did not receive the MS diagnosis (see Fig. 2).

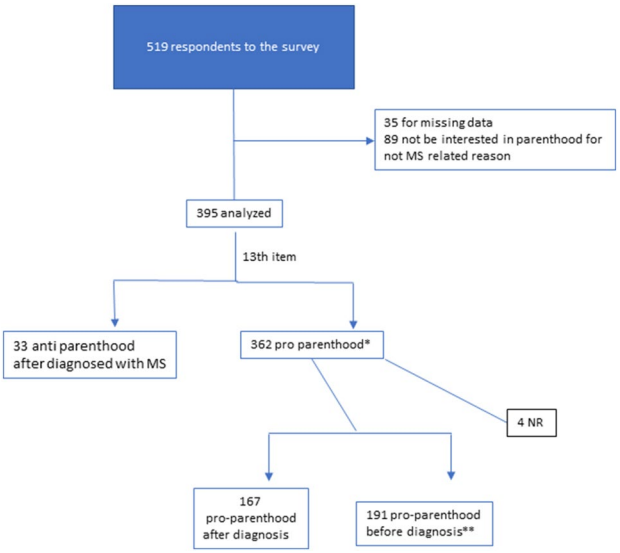


Fig. 1 Survey sample and distribution of patients according to the desire to become parent investigated by Q13. *"Pro-parenthood" definition: desire to become parent. *NR*: not respondents

Frequency of a second child

Among the 147 respondents already diagnosed with MS at the time they had the first child, 131 answered to the item "Do you have a second child?"; of them 51/131 (38%) answered positively and 80/131 (62%) answered negatively.

Among the 139 respondents that were not yet diagnosed with MS at the time they had the first child, 125 answered to the item "Do you have a second child?"; of them 83/125 (67%) answered positively and 42/125 (33%) answered negatively. Among those 83 pwMS who had the second child, 70/83 (85%) were still without the MS diagnosis and 13/83 (15%) had been already diagnosed with MS (see Fig. 2).

The frequency of a second child in pwMS after diagnosis was 38% compared to 67% in people without yet the MS diagnosis (see Fig. 2).

Frequency of a third child

Among pwMS having had two children and already diagnosed by the time of the first child, 32/51 answered to the item "Do you have a third child?"; of them, 8/32 (25%) answered positively and 24/32 (75%) answered negatively.

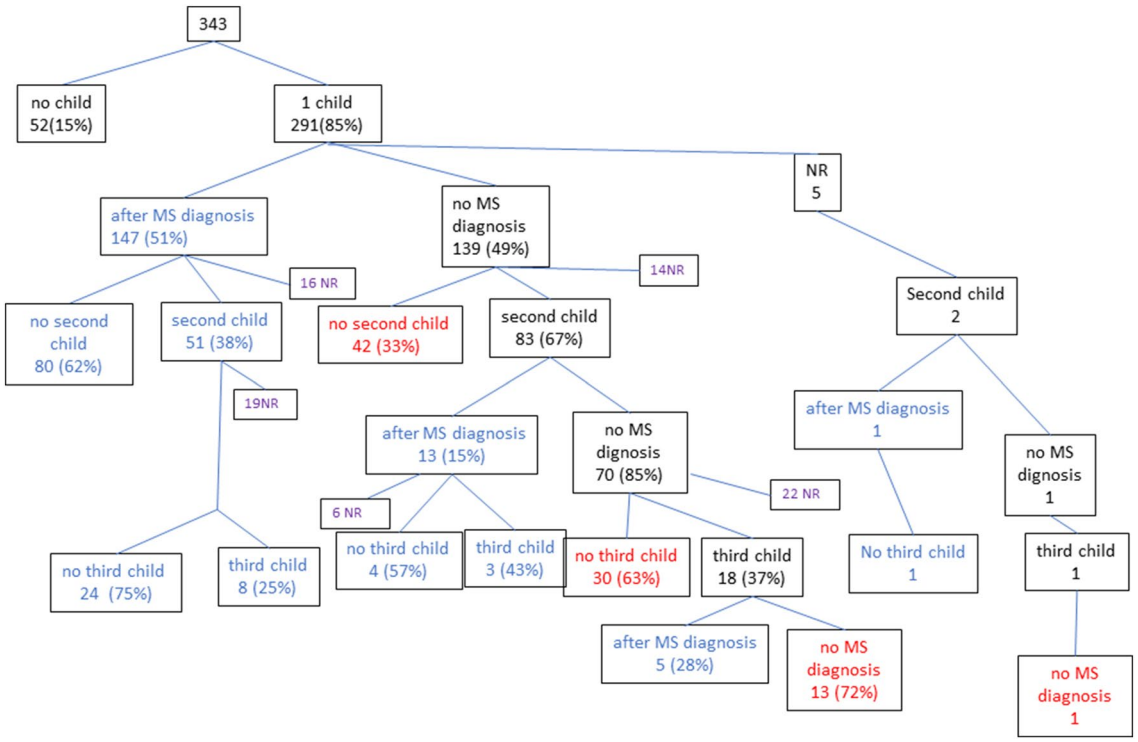


Fig. 2 Frequencies of first, second and third child in "pro-parenthood" with respect to MS diagnosis time point. *NR* not respondents

Among people having had two children, but not yet diagnosed with MS, 48/70 answered to the item "Do you have a third child?"; of them, 18/48 (37%) answered positively and 30/48 (63%) answered negatively. Among those 18 people who had the third child, 13/18 (72%) were still without the MS diagnosis and 5/18 (28%) had been diagnosed with MS.

Among those 13/83 pwMS who had been diagnosed between the first and second childbirth, 7/13 answered to the item "Do you have a third child?"; of them, 3/13 answered positively and 4/13 answered negatively (see Fig. 2).

Working status and education

In "pro-parenthood", only 54/362 (15%) pwMS answered to the item investigating about working activity and 22/54 (41%) were employed; only 55/362 (15%) pwMS answered about the item on education and 25/55 (45%) declared 13 years of school and 18/55 (33%) > 13 years.

Discouragement to become parent

Among "pro-parenthood", 349/362 (96%) answered to the item "After MS, have you been discouraged to become parent?"; of them, 55/349 (16%) were discouraged to become parent after diagnosis, more frequently by medical personnel (neurologist/physician), mainly due to concerns for the effects of pregnancy on MS. PwMS discouraged to become parent were more frequently women, significantly older by the survey time and younger at diagnosis with respect to not discouraged pwMS (see Table 2); 28/55 had already a child when discouraged and 27/55 had no children. Among 55 pwMS that were discouraged to have children, 45/55 answered the item investigating about DMT intake when they were discouraged; among them 20/45 pwMS were treated either with glatiramer acetate or interferons, 15/45 were treated with drugs considered potentially unsafe during pregnancy (teriflunomide, cyclophosphamide, fingolimod, alemtuzumab, dimethylfumarate and natalizumab) and 10/45 were under "other" treatment.

Delay of decision to become parent

In "pro-parenthood after diagnosis", 118/167 (71%) admitted that the diagnosis did not delay the decision to become parent.

164/167 (98%) answered the item investigating which DMT was taken by the time of parenthood decision and 86/164 (52%) declared to be treated with interferon beta or glatiramer acetate (DMTs considered "safe" for pregnancy) and 34/164 (21%) declared not to be treated.

Pregnancy planning

In the "pro-parenthood" group, 311/362 (86%) answered the item "Did your physician advise you to plan pregnancy?"; only 123/311 (39%) were counseled by their treating physician to plan pregnancy and to avoid unplanned pregnancy (no significant differences in level of education were found between pwMS advised (123) and those not advised (188) to plan pregnancy, $p = 0.094$). 115/123 of pwMS counseled to plan pregnancy answered to the item investigating whether they had children or not: 25/123 did not have and 90/123 pwMS did have children; 31/90 had the first child before having been diagnosed with MS and 59 after being diagnosed with MS. Therefore, in our sample, we have 31 pwMS with already a child when they were advised to plan pregnancy.

Age at first child: "pro-parenthood after diagnosis" vs "pro-parenthood before diagnosis"

Age at 1st child birth was higher in the "pro-parenthood after diagnosis" than in "pro-parenthood before diagnosis", respectively, 32.2 (5.3) vs 27.9 (5.1) years, $p < 0.001$; this difference was still significant after adjusting for age at diagnosis ("pro-parenthood after diagnosis" 34.6 (0.6) vs "pro-parenthood before diagnosis" 26.6 (0.5), $p < 0.001$).

We compared the age at first child birth of our sample with the mean age at first child birth of the Italian women

Table 2 Demographic and clinical characteristics of pwMS discouraged (55) and not discouraged (294) to become parent

N	Discouraged 55	Not discouraged 294	*p*
Sex: F (*n*, %)	51/55 (92.7%)	198/294 (67.4%)	**< 0.001**
Age (M, SD)	41.7 ± 9.2	41.8 ± 10.2	0.964
≥ 13 years of education (*n*, %)	43/55 (78.2%)	244/294 (83.0%)	0.392
Age at onset (M, SD)	24.9 ± 7.4	28.9 ± 9.3	**0.003**
Age at diagnosis (M, SD)	28.1 ± 7.7	31.8 ± 9.7	**0.007**
pwMS referring relapses (*n*, %)	46/55 (83.6%)	214/280 (76.4%)	0.241
pwMS referring progression (*n*, %)	20/49 (40.8%)	103/279 (36.9%)	0.603
pwMS referring maximum walk distance > 500 m (*n*, %)	24/54 (44%)	171/287 (59.6%)	0.527

from ISTAT (https://www.istat.it/it/files//2011/10/testointegrale200807011.pdf): our sample of women with MS who had the first child after diagnosis were older compared to general population of Italian women (32.1 vs 31.4); however, because we do not have a SD for the ISTAT data we cannot conclude whether this difference is significant or not. Considering factors potentially influencing the age at first child birth, we performed a further analysis correcting for age at diagnosis, comparing age at first child in the "pro-parenthood before" and "pro-parenthood after diagnosis" according to disease phenotype (only relapsing or only progressive), and walking distance > or < to 500 m: for any comparison, age at 1st child was significantly higher in the "pro-parenthood after diagnosis" subgroup (see Table 3).

Adoptions

In the "pro-parenthood" group, 348/362 (96%) answered the question "Have you considered to adopt a child?" and only 92/348 (26%) of them considered child adoption, especially for a personal or health-related choice independent of MS. Otherwise 256/348 (74%) did not consider child adoption mainly (200/256 [78%]) for reasons independent of MS. Only 272/348 (78%) answered to the item "have you adopted a child?"; of them, only 4/272 (1.5%) really adopted a child, for a personal choice not disease-related.

Abortions

321/362 (89%) "pro-parenthood" answered the item "Did you have abortions" and 80/321 (25%) had abortions. Of them, 69/80 (86%) answered to the item "Was the abortion spontaneous or voluntary" and 51/69 (74%) reported at least a spontaneous abortion, mainly in the first trimester of pregnancy. 29/321 (9%) of "pro-parenthood" performed at least a voluntary termination of pregnancy. Among the 29 pwMS who had a voluntary abortion, 3pwMS did not have children; 12/26 had at least a child before MS diagnosis, 13/26 had at least a child after diagnosis and 1 pwMS did not answer at the item investigating the timing of diagnosis with respect to the first child birth.

Table 3 Age at first child in pwMS pro-parenthood before and after diagnosis

	Age at first child birth[a]		*p*
	Pro-parenthood before diagnosis	Pro-parenthood after diagnosis	
Relapsing pwMS	26.7 (0.6)	34.1 (0.8)	< 0.001
Progressive pwMS	25.9 (0.8)	35.9 (1.4)	< 0.001
Walking > 500 m	27.0 (0.7)	34.2 (0.8)	< 0.001
Walking < 500 m	25.8 (0.6)	34.8 (0.9)	< 0.001

[a]Adjusted for age at diagnosis

Relapsing and progressive sub-analysis

377/395 (95%) answered the item investigating about the presence of relapses and 286/377 (76%) stated to have a relapsing MS phenotype at survey time. 373/395 (94%) answered the item investigating about the presence of progression and 151/373 (40%) reported to have a progressive course of the disease (see Fig. 3a). The two answers about relapses and progression were not mutually exclusive.

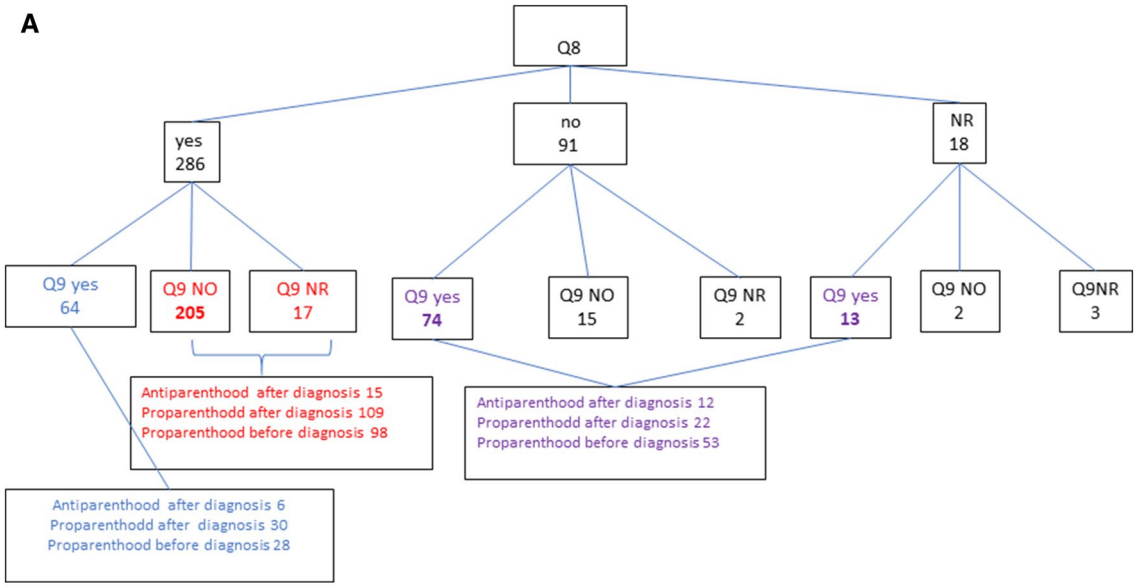
Among 286 relapsing pwMS, 21/286 (7%) belonged to the subgroup "anti-parenthood after diagnosis"; 139/286 (49%) were in "pro-parenthood after diagnosis" subgroup; 126/286 (44%) were in "pro-parenthood before diagnosis" subgroup. 91/377 (24%) respondents declared not to have relapses. 18 people did not answer the item Q8 investigating the presence of relapses; of them, 15/18 did answer the item Q9 investigating the presence of progression and 13/15 stated to be progressive while 2/15 declared not to be progressive. Among those answering "yes" (74 + 13) to item Q9 about progression, 12/87 (14%) were in the "anti-parenthood after diagnosis" subgroup; 22/87 (25%) were in "pro-parenthood after diagnosis" subgroup; 53/87 (61%) were in "pro-parenthood before diagnosis" subgroup (see Fig. 3a). Considering those people answering to have only a relapsing or only a progressive phenotype, 222 patients were only relapsing and 87 were only progressive while 64 were both relapsing and progressive (see Fig. 3a). The patients' distribution according to the clinical phenotype (exclusively relapsing vs exclusively progressive) was significantly different ($p < 0.001$) in the three subgroups considering the parenthood desire ("anti-parenthood after diagnosis", "pro-parenthood before" and "pro-parenthood after diagnosis") showing a higher proportion of progressive patients in the "anti-parenthood after diagnosis" subgroup (see Fig. 3b).

373/395 (94%) pwMS replied to the item Q9 "presence/absence of progression", referring to their clinical phenotype at the time of the survey and 151/373 (40%) declared a progressive course: 18/151 (12%) belonged to the "anti-parenthood after diagnosis" subgroup; 52/151 (34%) were in "pro-parenthood after diagnosis" subgroup; 81/151 (54%) were in "pro-parenthood before diagnosis" subgroup (see Fig. 3b).

"Anti-parenthood after diagnosis" vs "pro-parenthood after diagnosis"

- The "anti-parenthood after diagnosis" had a mean age at onset and diagnosis significantly higher than the "pro-parenthood after diagnosis" (respectively, 26.3 vs 23.6, $p = 0.016$; 29.2 vs 25.2, $p = 0.001$);

A



B

	Anti-parenthood after MS diagnosis	Pro-parenthood after MS diagnosis	Pro-parenthood before MS diagnosis
2A 222 100%	15 6,76%	109 49,10%	98 44,14%
2B 87 100%	12 13,79%	22 25,29%	53 60,92%
2C 64 100%	6 9,38%	30 46,88%	28 43,75%
Total 373 100%	33 8,85%	161 43,16%	179 47,99%
2A vs 2B p<0,001 2C vs 2B p=0,022 2C vs 2A p=0,773			

Fig. 3 **a** pwMS referring relapses (item Q8), progression (item Q9) or both relapses and progression and their distribution in "anti-parenthood" or "pro-parenthood" (before or after MS diagnosis) subgroups. *Red* only relapsing (205 + 15 + 2) = 222; *violet* only progressive (74 + 13) = 87; *blue* relapsing + progressive = 64; *NR* not responding. **b** Proportion of relapsing, progressive and relapsing + progressive pwMS in each subgroup and age-adjusted comparison between groups, *2A* only relapsing (205 + 17) = 222; *2B* only progressive (74 + 13) = 87; *2C* relapsing + progressive (147 + 13 + 5 + 1) = 166

- the age at diagnosis was inversely correlated with the pro -parenthood attitude (OR 0.90, CI 95% 0.85–0.96 $p = 0.001$);
- the age at diagnosis was positively correlated with the age at 1st child birth in "pro-parenthood after diagnosis" ($r = 0.55$ $p < 0.001$) also in "pro-parenthood before diagnosis" but with a weaker correlation ($r = 0.19$ $p = 0.016$);
- the educational level was not significantly different ($p = 0.423$);
- a lower percentage of "anti-parenthood after diagnosis" compared to "pro-parenthood after diagnosis" declared to walk over 500 m without rest or assistance (45.5% vs 68.5 $p = 0.012$);
- The age for pwMS needing a walking support was not significantly different ($p = 0.286$);
- see Fig. 3a, b for patients' distribution in the "pro-parenthood before diagnosis", "pro-parenthood after diagnosis" and in the "anti-parenthood after diagnosis" subgroups according to clinical course.

Discussion

Our survey study, recruiting members of a web community supervised by Neurologists and Psychologists, explored the parenthood motivation in a subgroup of 395 Italian pwMS interested in parenting issues. Despite having addressed the survey to both sexes, recognizing their mutual role in reproductive decisions, participants were principally women, as consistent with the predominant female susceptibility to MS [1]. The majority of respondents were (1) not in an advanced stage of illness, as shown by a prevalent relapsing–remitting course; (2) not reporting walking restriction; (3) using (in about half of the cases) a first-line DMT, according to AIFA (https://www.agenziafarmaco.gov.it). Despite the reassuring data on pregnancy in pwMS, our results showed that about 7% (33) of respondents of our sample declared that they never wanted to become parent because of MS, being representative of the most dramatic impact of diagnosis on life project. In agreement with previous studies [15, 16], although only a small percentage of pwMS reported to have been frankly discouraged to procreate after the diagnosis, more frequently the negative influences were provided by medical personnel (physician/neurologist) for concerns about the effects of pregnancy on MS. Furthermore, our data highlighted and confirmed a gap in the doctor–pwMS communication on reproduction, pregnancy, and childbearing issues [8, 9]. In fact, solely a minority of participants received doctor counseling to plan pregnancy or to avoid accidental maternity. In this respect, in our sample, having had a child before or after MS diagnosis was not a major issue to advise or not to plan pregnancy.

A minority of participants reported abortions: most of them occurred spontaneously during the first trimester of pregnancy, in accordance with previous studies revealing not increased rate of miscarriages in MS women [17]. Only a small number of participants, concerned about the inability to raise the baby, reported induced abortions differently from a recent survey where the reasons of the medical/surgical abortions were unclear [12]. We considered reliable these findings as the web tool may represent a comforting space to debate on disease-related concerns overcoming the inconvenience of pwMS–doctor frontal approach [18]. It is worthwhile to consider that the pro-parenthood or anti-parenthood attitude refers to the desire of becoming parents, independently by the concrete realization of this desire; in the study definition, "anti-parenthood" are those people who never desired to become parents: either for personal reasons (and these patients were excluded from the analyses) or for MS-related reason; therefore, women having an abortion may be still "pro-parenthood" but may decide to have an abortion for several reasons (being unmarried, interference with job stabilization, unstable relationship with partner, economic problems, etc.).

In our MS sample was also confirmed the low propensity for adoption observed in the general Italian population (http://www.centrostudinisida.it/Statistica/Adozione_affidamento.html).

Different from previous studies [8, 19], only a small percentage of our population rejected parenting as a disease consequence; indeed, 51% of the respondents had already received the MS diagnosis at the time of becoming parent for the first time while 49% had not yet been diagnosed with MS. However, among those having had a second child, 85% did not know to have MS and 38% were already diagnosed, showing a decrease in frequency of second child after the diagnosis of MS. This result is in agreement with the findings of a Portuguese study where the planned pregnancy number of MS women decreased immediately after the diagnosis, suggesting important implications of disease disclosure on life projects [20].

Considering the significant difference between the proportion of relapsing and progressive patients in the "anti-parenthood" subgroup (7% vs 14%), in the "pro-parenthood" after diagnosis subgroup (49% vs 25%) and in the "pro-parenthood" before diagnosis (44 vs 61%), we suggest that a worse disease course, that drove to a progressive phenotype at survey time, might have negatively impacted on parenthood desire, probably triggering a prospective fear of "worsening" in the near future.

Supporting this evidence, in our study, we found that not-relapsing pwMS, with a positive attitude towards parenthood, more frequently elaborated the desire for family before the diagnosis. Moreover, we found that "anti-parenthood after diagnosis" were older than the "pro-parenthood after diagnosis" (respondents who processed the decision to become parent after receiving the diagnosis) at disease onset and diagnosis, showing an inverse correlation between age at diagnosis and parenthood attitude. These results suggested that, considering the MS age at diagnosis ranging from 20 to 40 years old, a later onset and diagnosis could negatively interfere with the development of parenthood desire and motivation. Moreover, younger pwMS might have a better copying with the disease, with a better perceived QoL [21], and through the mitigating role of resiliency [22].

PwMS in "pro-parenthood after diagnosis" subgroup declared that the disease awareness did not delay the desire to become parent; probably the prevalence of interferon beta or glatiramer acetate in this population or the complete lack of exposure to medications, at the moment of parenthood choice, might have influenced the result; indeed, we can speculate that pwMS requiring a first-line DMT might have had a better disease course thus not impacting on their parenthood decision.

Limits

An important limitation of this survey is part of the general limitation of Social Networking Sites for collecting data that may introduce self-selection bias, with consequent generalization issues; however, to gauge any bias in recruitment, we compared the demographic characteristics (age, F/M ratio) of our sample to data from the "Barometro-2018" of AISM.

The current study design was a cross-sectional survey and hence subject to selection, recall, and information bias. It may represent the patient voice, but the data are based on subjective self-reports, and are derived from a convenience sample. Furthermore, the mix of patients is representative of SMsocialnetwork and not necessarily of the MS population at large.

In contrast to face-to-face interview, online surveys do not allow to deepen the reasons leading to each choice in the answers and to have complete information from any respondent; on the other side, online surveys allow to involve many people in a short time.

Another important limitation is the lack of a healthy control group which could have strengthened some of the conclusion; however, we tried to overcome some criticality due to this lack by comparing some data to data derived from ISTAT referring to the Italian general population.

Conclusions

In conclusion, in our sample, MS diagnosis may overlap with the timeframe of parenthood decision interfering with the elaboration of family desire and its realization. The process of psychological acceptance and adjustment, after the diagnosis of MS, requires a time to overcome the negative representation of the disease by implementing coping strategies for positive adaptation [23, 24]. In particular, MS diagnosis impacted dramatically on the life project of 7% of our sample that decided not to have children because of the disease; moreover, our data suggest that dealing with MS impacted more on having the second child than the first one.

The negative influences on family planning were provided mainly by medical personnel (physician/neurologist) for concerns about the effects of pregnancy on MS. Therefore, a prompt and skilled counseling focused on parenthood-related issues may support the tuning into needs of pwMS, encouraging parenting. Hence, in accordance with a recent study that showed that 47% of respondents to an online survey felt inadequately informed about treatment possibilities for MS while planning to start a family [12], our data suggest that an adequate informed support of pwMS is necessary, especially right after the diagnosis, to reduce the negative impact of an inappropriate disease awareness on parenthood motivation and life decisions.

Compliance with ethical standards

Conflicts of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

References

1. Compston A, Coles A (2002) Multiple sclerosis. Lancet 359(9313):1221–1231
2. Polman CH, Reingold SC, Banwell B, Clanet M, Cohen JA, Filippi M, Fujihara K, Havrdova E, Hutchinson M, Kappos L, Lublin FD, Montalban X, O'Connor P, Sandberg-Wollheim M, Thompson AJ, Waubant E, Weinshenker B, Wolinsky JS et al (2011) Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. Ann Neurol 69(2):292–302
3. Dennison L, Moss-Morris R, Chalder T (2009) A review of psychological correlates of adjustment in patients with multiple sclerosis. Clin Psychol Rev 29(2):141–153
4. Janssens AC, van Doorn PA, de Boer JB, van der Meché FG, Passchier J, Hintzen RQ (2003) Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. Acta Neurol Scand 108(6):389–395
5. Santangelo G, Sacco R, Siciliano M, Bisecco A, Muzzo G, Docimo R, De Stefano M, Bonavita S, Lavorgna L, Tedeschi G, Trojano L, Gallo A (2016) Anxiety in multiple sclerosis: psychometric properties of the state-trait anxiety inventory. Acta Neurol Scand 134(6):458–466. https://doi.org/10.1111/ane.12564 **(Epub 2016 Feb 1)**
6. Sepúlveda M, Fernández-Diez B, Martínez-Lapiscina EH, Llufriu S, Sola-Valls N, Zubizarreta I, Blanco Y, Saiz A, Levy D, Glimcher P, Villoslada P (2017) Impairment of decision-making in multiple sclerosis: a neuroeconomic approach. Mult Scler 23(13):1762–1771
7. Tavazzi E, Rovaris M, La Mantia L (2014) Drug therapy for multiple sclerosis. CMAJ 186(11):833–840. https://doi.org/10.1503/cmaj.130727
8. Bove R, Alwan S, Friedman JM, Hellwig K, Houtchens M, Koren G, Lu E, McElrath TF, Smyth P, Tremlett H, Sadovnick AD (2014) Management of multiple sclerosis during pregnancy and the reproductive years: a systematic review. Obstet Gynecol 124(6):1157–1168. https://doi.org/10.1097/AOG.0000000000000541
9. Coyle PK (2016) Management of women with multiple sclerosis through pregnancy and after childbirth. Ther Adv Neurol Disord May 9(3):198–210. https://doi.org/10.1177/1756285616631897
10. Ferraro D, Simone AM, Adani G, Vitetta F, Mauri C, Strumia S, Senesi C, Curti E, Baldi E, Santangelo M, Montepietra S, Immovilli P, Guareschi A, Neri W, Granella F, Caniatti L, Tola MR, Motti L, Pesci I, Montanari E, Sola P (2017) Definitive childlessness in women with multiple sclerosis: a multicenter study. Neurol Sci 38(8):1453–1459. https://doi.org/10.1007/s10072-017-2999-1
11. Alwan S, Yee IM, Dybalski M, Guimond C, Dwosh E, Greenwood TM, Butler R, Sadovnick AD (2013) Reproductive decision making after the diagnosis of multiple sclerosis (MS). Mult Scler 19(3):351–358
12. Rasmussen PV, Magyari M, Moberg JY, Bøgelund M, Jensen UFA, Madsen KG (2018) Patient awareness about family planning

represents a major knowledge gap in multiple sclerosis. Mult Scler Relat Disord 24:129–134
13. Lavorgna L, Russo A, De Stefano M, Lanzillo R, Esposito S, Moshtari F, Rullani F, Piscopo K, Buonanno D, Brescia Morra V, Gallo A, Tedeschi G, Bonavita S (2017) Health-related coping and social interaction in people with multiple sclerosis supported by a social network: pilot study with a new methodological approach. Interact J Med Res 14(2):e10
14. Dong Y, Peng CY (2013) Principled missing data methods for researchers. Springerplus 2(1):222. https://doi.org/10.1186/2193-1801-2-222
15. Borisow N, Doring A, Pfueller CF, Paul F, Dorr J, Hellwig K (2012) Expert recommendation to personalization of medical approaches in treatment of multiple sclerosis: an overview of family planning and pregnancy. EPMA J 22(1):9 3(
16. Smeltzer SC (2002) Reproductive decision making in women with multiple sclerosis. J Neurosci Nurs 34:145–157
17. Hellwig K (2014) Pregnancy in multiple sclerosis. Eur Neurol 72(Suppl 1):39–42. https://doi.org/10.1159/000367640
18. Lavorgna L, Moccia M, Russo A, Palladino R, Riccio L, Lanzillo R, Brescia Morra V, Tedeschi G, Bonavita S (2017) Health-care disparities stemming from sexual orientation of Italian patients with multiple sclerosis: a cross-sectional web-based study. Mult Scler Relat Disord 13:28–32
19. Albrecht P, Fischer D, Moser A (2010) Multiple sclerosis and pregnancy: what does the patient think? a questionnaire study. BMC Res Notes 3(3):91
20. Carvalho AT, Veiga A, Morgado J, Tojal R, Rocha S, Vale J, Sa MJ, Timoteo A (2014) Multiple sclerosis and motherhood choice: an observational study in Portuguese women patients. Rev Neurol 16(12):537–542 59(
21. Lanzillo R, Chiodi A, Carotenuto A, Magri V, Napolitano A, Liuzzi R, Costabile T, Rainone N, Freda MF, Valerio P, Brescia Morra V (2016) Quality of life and cognitive functions in early onset multiple sclerosis. Eur J Paediatr Neurol 20(1):158–163
22. Rainone N, Chiodi A, Lanzillo R, Magri V, Napolitano A, Morra VB, Valerio P, Freda MF (2017) Affective disorders and Health-Related Quality of Life (HRQoL) in adolescents and young adults with Multiple Sclerosis (MS): the moderating role of resilience. Qual Life Res 26(3):727–736
23. Amato MP, Portaccio E (2015) Fertility, pregnancy and childbirth in patients with multiple sclerosis: impact of disease-modifying drugs. CNS Drugs 29(3):207–220
24. Tan-Kristanto S, Kiropoulos LA (2015) Resilience, self-efficacy, coping styles and depressive and anxiety symptoms in those newly diagnosed with multiple sclerosis. Psychol Health Med 20(6):635–645