

# European Women With Multiple Sclerosis Feel Unprepared and Uneducated About Family Planning and Their Ability to Have Children – How Do We Improve Patient Education?

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Multiple sclerosis (MS) is a disabling disease affecting the central nervous system. Despite the high frequency of this disease in women of childbearing age, it has previously been found that female patients with MS are often uninformed regarding the effects of pregnancy on MS and there is little available research on family planning decisions in females with MS. In this commentary we examine the results of a recent multi-country study, carried out by Wakefield Research for Teva Pharmaceuticals, of 1,000 women, aged 25–35 years, who were diagnosed with relapsing forms of MS (RMS) in the last 5 years. The survey sampled 200 women from each of the following five countries: Germany, Italy, the Netherlands, Spain and the United Kingdom. Results from this survey highlight a lack of open communication regarding family planning between women in Europe with MS and healthcare professionals (HCPs), and show that insufficient information on family planning is being provided to the majority of those surveyed. We discuss the importance of family planning for European women with MS, and their top concerns regarding this issue. In addition, we outline how family planning concerns are addressed with HCPs, and discuss how family planning education for patients with MS can be improved.

## Keywords

Multiple sclerosis (MS), relapsing forms of MS (RMS), pregnancy, childbearing, childbirth, family planning

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Multiple sclerosis (MS) is a chronic autoimmune condition affecting the central nervous system (CNS). The most recent Atlas data estimated that the number of people with MS worldwide was 2.3 million.<sup>1</sup> Prevalence rates of the disease range from 2.1 per 100,000 in Sub-Saharan Africa, to greater than 100 per 100,000 in Northern Europe and North America.<sup>2</sup> As the typical onset of MS is between 20–40 years of age,<sup>3</sup> and MS is 2–3 times as common among women than men,<sup>2</sup> MS disproportionately affects women of childbearing age.

## Multiple sclerosis and pregnancy

Historically, women with MS were discouraged from having children as pregnancy was thought to negatively affect the disease course of MS.<sup>4</sup> Over the past few decades, studies have shown that the opposite is true, and that pregnancy is associated with fewer relapses followed by a peak in relapse incidence in the early postpartum period.<sup>4–6</sup> The Pregnancy in Multiple Sclerosis (PRIMS) study (n=254) found that in women with MS, the rate of relapse declines during pregnancy, increasing during the first three months postpartum before returning to the pre-pregnancy rate.<sup>5</sup> Similarly, a meta-analysis using data from 1,221 pregnancies across 13 studies, found the mean relapse rate decreased from 0.435 to 0.182 (p<0.0001) during pregnancy, and increased to 0.703 in the postpartum period (p<0.0001).<sup>6</sup> In an analysis of 893 pregnancies in 674 women, the annualised relapse rate was 0.32, which decreased in the first trimester to 0.25, and 0.13 in the third trimester of pregnancy (p<0.001).<sup>4</sup> In the first 3 months of the postpartum period, the relapse rate increased to 0.61 (p<0.001). Interestingly, in this study, disease-modifying therapy (DMT) exposure in the 2-year pre-conception period was found to be independently protective against early postpartum relapse.<sup>4</sup>

Women with MS should be reassured that pregnancy does not appear to be harmful, and may even be beneficial to their MS.<sup>7</sup> Pregnancy after MS onset has been associated with slower long-term disability progression, although this effect may be due to a higher propensity towards child bearing in women with milder disease.<sup>8</sup> In an analysis of 445 women with MS, women who had given birth (n=184) had a significantly lower risk of reaching an Expanded Disability Status Scale (EDSS) score of 4.0 or more (hazard ratio [HR]=0.552, 95% confidence interval [CI] 0.356–0.857, p=0.008) when compared with women who had not had children (n=261).<sup>8</sup>

While pregnancy is not harmful for women with MS, specific management questions and concerns surround the pre-pregnancy, pregnancy and postpartum periods. These concerns are complicated by the use of DMTs and other medications for symptom relief. Unfortunately,

there is limited information regarding the safety of approved DMTs on fertility, pregnancy and lactation in patients with MS,<sup>9</sup> and no DMTs are currently recommended for use during conception, pregnancy or while breastfeeding.<sup>10</sup> While there are currently no recognised and implemented guidelines for the management of MS through pregnancy and childbirth, two recent reviews provide management recommendations for patients with MS around the pre-pregnancy, pregnancy and postpartum periods in the MS treatment era.<sup>10,11</sup> Clinical management of women with MS should be individualised to optimise both the women's reproductive outcomes and the course of disease.<sup>11</sup>

### The impact of multiple sclerosis on family planning

MS is most often diagnosed at the time in which many people may be thinking of starting, or extending, their family. Common concerns affecting the decision of MS patients to have a child include: patient's ability to take care of the baby, fear of MS being inherited by the child, and fear of burdening a partner.<sup>12</sup> While family planning is an important topic for patients with MS, there is little information in the literature regarding family planning decisions in patients with MS,<sup>13</sup> despite the higher frequency of this disease in females of childbearing age.<sup>14</sup> An observational study of 100 Portuguese women with MS found that 77% of women had fewer pregnancies than they had intended before MS diagnosis (i.e., women changed the number of children they were planning to have) and 43% believed that pregnancy could worsen the disease;<sup>13</sup> however, it should be noted that possible memory bias is a limitation of this study. Similarly, in a qualitative study of 15 pregnant women with MS, patients reported that their MS diagnosis affected their previous plans for number of children as well as spacing of pregnancies.<sup>15</sup> Although study participants become pregnant (despite their concerns regarding the effect of pregnancy on the course of their disease), they continued to perceive their decision as risky. A recent questionnaire administered to 13,312 registrants of the North American Research Committee on Multiple Sclerosis (NARCOMS) database found that among 5,949 participants, the majority of respondents (79.1%) did not become pregnant following diagnosis of MS, and for 34.5% the decision to not get pregnant was due to MS-related reasons.<sup>12</sup> Data from these limited studies suggest that a diagnosis of MS can significantly impact patients' decisions to have children, the number of children they have, and the spacing of their pregnancies.<sup>12,13,15</sup>

### Lack of patient information about the effect of multiple sclerosis on pregnancy

For female MS patients to make their own independent and well-informed family planning decisions, it is important that they are well educated on the effects of MS on pregnancy; however, it has previously been reported that there is a lack of knowledge in female patients with MS regarding this topic.<sup>16,17</sup> In a study by Albrecht et al., patients were asked four multiple-choice questions concerning MS and pregnancy. Of 146 patients, only seven (4.8%) correctly answered all four questions.<sup>16</sup> An emerging theme from qualitative studies of women with MS and their childbearing experiences, has been concern regarding the limited access to information about relationships between MS and childbearing and receiving conflicting or incomplete information from healthcare professionals (HCPs).<sup>15,17,18</sup> The results of a recent multi-country study by Wakefield Research ([www.wakefieldresearch.com](http://www.wakefieldresearch.com)) for Teva Pharmaceuticals, further highlight a lack of open communication with HCPs, and insufficient information on family planning (Wakefield Research, data on file). In this study, 1,000 women, aged 25–35 years, who were diagnosed with relapsing forms of MS (RMS) in the last 5 years were surveyed on their plans to have a family and their experiences

during this process. The survey sampled 200 women between 10 August and 1 September 2017 from each of the following five countries: Germany, Italy, the Netherlands, Spain and the UK.

### Teva Pharmaceuticals EU survey methods

Survey respondents were selected from a global panel of patient populations and invited to participate via an email invitation and an online survey. Response to the survey was incentivised, and survey instruments were translated and localised for each country. To ensure eligibility, respondents in Germany, Italy, the Netherlands and the UK were administered a series of 17 classification and screening questions. A total of 15 classification questions were administered in Spain. Once eligibility requirements were met, participants were asked a total of 20 survey content questions. While results of any sample are subject to sampling variation, for the interviews conducted in this particular study, the chances are 95 in 100 that a survey result does not vary, plus or minus, by more than 3.1 percentage points at the overall level, and 6.9 percentage points in each country from the result that would be obtained if interviews had been conducted with all persons in the universe represented by the samples. We discuss the results of the survey in further detail.

### Results of the Wakefield Research for Teva Pharmaceuticals study

#### The importance of family planning

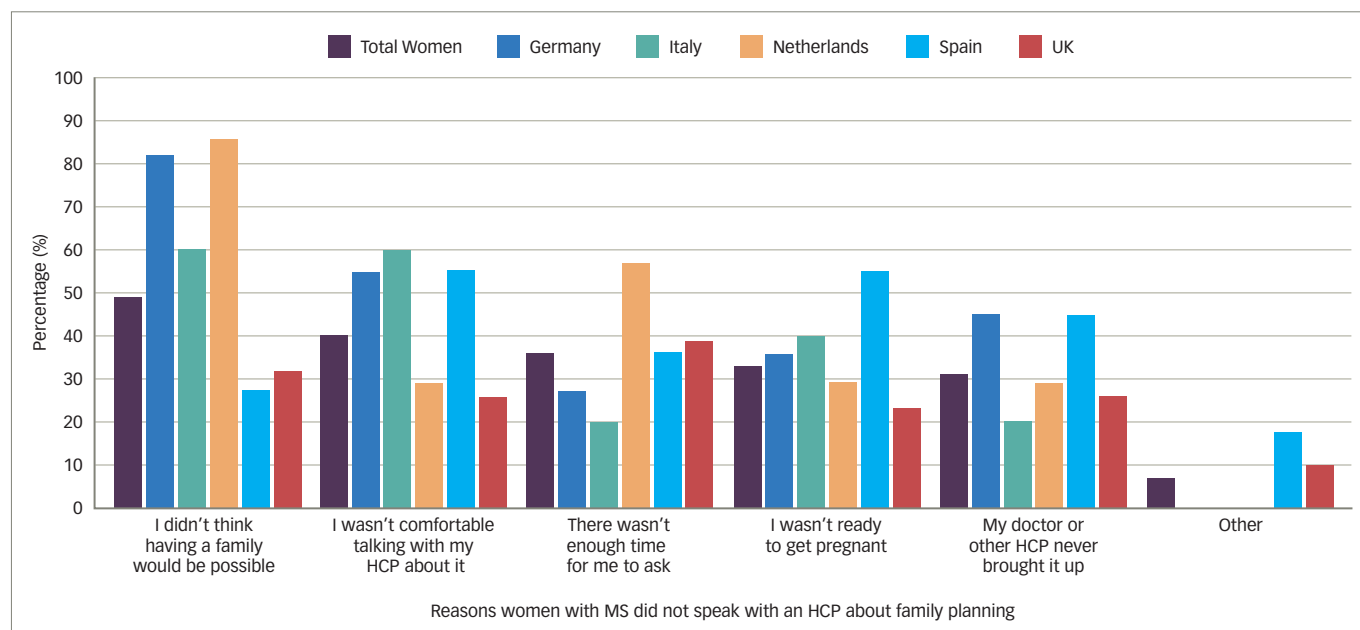
Family planning is an important topic for women diagnosed with MS. For 90% of women with MS surveyed, having a family is important, and 80% currently have plans to have a child, on average within the next 3 years. When specifically asked, the majority of women feel or felt unprepared for the physical (87%) and emotional (84%) challenges of family planning with MS. The large majority of women surveyed have plans to have a child soon, so it is concerning that so many feel unprepared for the challenges of having a family.

#### Important concerns regarding family planning in women with multiple sclerosis

For women with MS, the ability to have children is a top concern, second only to their ability to care for themselves. In women surveyed, the areas of top concern included: their ability to care for themselves (30%), their ability to have children (21%), their personal relationships (20%), and their ability to care for their current or future children (17%). Overall, the most important family planning concerns for women with MS at the time of diagnosis were: the potential to pass MS on to their children (62%), their ability to care for children (55%), and whether or not they would be able to conceive (53%). The possibility of passing MS to children appears to be a common concern in women with MS; however, patients should be reassured that MS is not considered to be hereditary.<sup>10</sup> The age-adjusted lifetime risk of an offspring developing MS is around 4% if one parent has MS (the same rate as the frequency of birth defects in the general population).<sup>7</sup> The lifetime risk of MS in the general population, using age- and sex-specific incidence rates from published studies, has been reported to be 2.5% for females, and 1.4% for males.<sup>19</sup> Similarly, while many women are concerned whether they will be able to conceive, MS appears to have no physiological effect on fertility.<sup>20</sup> The results of a recent observational study of motherhood decisions in 100 Portuguese women with MS, support the lack of effect of MS on fertility.<sup>13</sup> While 28% of women in the study had already had their intended number of children, and it is not reported how many women tried to start a family or increase their family size, 43% became pregnant following their MS diagnosis.<sup>13</sup>

Women's top concerns about raising a child, specifically in relation to their MS, are: they won't have enough energy to care for their child

Figure 1: Reasons that women did not speak to their doctor or another healthcare professional about family planning\*



\*Directional findings only (n=70). HCP = healthcare professional; MS = multiple sclerosis; UK = United Kingdom.

(59%), their child's safety will be compromised (58%), and that their child will develop MS because they have it (58%). While it is unknown what percentage of survey respondents were taking a DMT, family planning was an important factor in MS treatment decisions in 89% of women, and more than half (52%) reported family planning as very important in treatment decisions.

### Addressing family planning concerns with healthcare professionals

For women with MS, the need for accurate information on family planning begins at diagnosis, according to the survey findings (Wakefield Research, data on file). At the time of their diagnosis, 88% of women with MS were concerned they would not be able to have children. Misconceptions about the ability to get pregnant can prevent women with MS from getting necessary family planning information. Additionally, lack of communication between patients and HCPs may stem from uncertainty as to who should start the conversation. Despite the importance of this topic, only 37% of women initiated the first family planning conversation with their doctor or other HCP. Discussions on family planning with their doctors or other HCPs, for most women with MS (79%), occurred while they are still in the planning phase of getting pregnant. For women with MS who had not spoken to an HCP about family planning (n=70), Figure 1 outlines the reasons given for not doing so. Almost half (49%) of these women said that they did not speak to an HCP because they didn't think that having a family would be possible.

Opportunities to get family planning information and discuss concerns with HCPs are often not taken (Wakefield Research, data on file). More than half of women (57%) who had any concern at the time of their MS diagnosis that they would not be able to have children, have not spoken to their general practitioner about family planning. More than 35% have not spoken about family planning to their neurologist or MS specialist; 68% haven't spoken to a nurse/MS nurse; and over half of women (53%) had not discussed family planning with a HCP other than their general practitioner, neurologist/MS specialist or nurse/MS nurse. While patients may not be using all available opportunities to

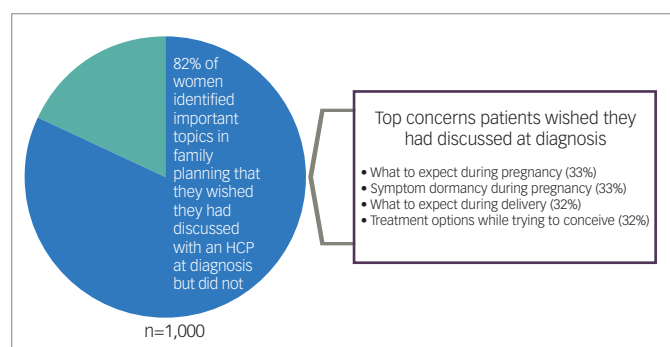
get information on family planning, nearly all women surveyed (97%) felt supported when discussing family planning with their doctor or other HCP.

For such an important topic, discussions on family planning may be brief, and there may not be much follow-up with patients. Nearly 18% of women with MS who spoke to their doctor or other HCP said their initial conversation about family planning with their HCP lasted 10 minutes or less. Amongst all the countries surveyed, women with MS who have spoken to a doctor or other HCP had an average of 6 follow-up conversations about family planning, however over a quarter of women (28%) had only had 1–2 follow-up conversations.

### Improving family planning education for multiple sclerosis patients

Women need access to information that can better educate them and help alleviate their concerns about having and raising children (Wakefield Research, data on file). It is important to note that, 45% of European pregnancies are unplanned,<sup>21</sup> and all female patients with MS must be counselled accordingly.<sup>11</sup> The vast majority of women with MS (81%) wish there was more, or better, family planning information for women with MS in general. A large majority of women (82%) identified important aspects of family planning that they wished their HCP had discussed at the time of their diagnosis such as: what to expect during pregnancy (33%), symptom dormancy during pregnancy (33%), what to expect during delivery (32%), and treatment options while trying to conceive (32%) (Figure 2). Among women who discussed family planning with an HCP at the time of their MS diagnosis, the most common topics they reported that were not covered included: preventing pregnancy/birth control (56%), breast feeding (56%), and treatment options while trying to conceive (50%). The lack of discussion in these areas is concerning, as the weighting between risk and benefit of stopping a DMT to get pregnant, particularly if it takes several months to conceive, is important and should always be done after detailed counselling with an experienced physician.<sup>22</sup> This same risk/benefit analysis should also be applied when making the decision to restart the medication immediately after delivery, or stay off medication in order to

**Figure 2: Family planning topics women wished they had discussed with their doctors at diagnosis**



HCP = healthcare professional

breastfeed.<sup>22</sup> The specific family planning topics women with MS want more, or better, information on are: what to expect during pregnancy (42%), what to expect during delivery (40%), trying to conceive (36%) and symptom dormancy during pregnancy (36%).

It is clear from these results that better education on family planning and pregnancy is needed for women with MS, but how do we improve patient education? Some recommendations for HCPs are outlined below.

- Starting at diagnosis, it is important to start an open dialogue about family planning as ‘the ability to have children’ is a top patient concern.
- HCPs must remember that all women with MS, of childbearing age, regardless of their current plans to have children, could potentially benefit from information on the effects of pregnancy on MS.
- Proactive conversations about disease and symptom management during the periods of conception, pregnancy and breastfeeding are especially important, particularly for women who are on a DMT or taking many medications to manage their symptoms.
- The conversation on family planning should be open and on-going as different issues may emerge at different stages in the family planning and reproductive cycle of the patient.
- Providing patients with resources on family planning and the interactions of MS and pregnancy can help to better inform, as well as fostering questions for future discussion.

With those tips in mind, and to further aid and improve patient education, Teva Pharmaceuticals and touchNEUROLOGY®/European Neurological Review have partnered together to publish toolkits for HCPs and female patients with MS, which are available to download.<sup>23,24</sup> For HCPs there is a guide to survey results and patient conversation,<sup>23</sup> while information for female patients includes:<sup>24</sup>

- Facts on MS and family planning for women with MS;
- Family planning questions for women with MS to ask their healthcare team; and
- Tips for women on family planning with MS.

### Concluding remarks

Family planning and the ability to have children is an important topic for women diagnosed with MS (Wakefield Research, data on file). A diagnosis of MS can significantly impact patients’ decisions to have children, the number of children they have, and the spacing of their pregnancies.<sup>12,13,15</sup> Despite the importance of family planning to women with MS, there is a little available research on family planning decisions in females with MS.<sup>13</sup> The Wakefield Research for Teva Pharmaceuticals survey of European women with MS found that the majority of women surveyed have plans to have a child soon, but feel unprepared for the challenges of having a family (Wakefield Research, data on file). The most important family planning concerns for women with MS at the time of diagnosis were: the potential to pass MS on to their children, their ability to care for children, and whether or not they would be able to conceive. The vast majority of women with MS wished there was more or better family planning information for women with MS in general, and a large majority identified important aspects of family planning that they wished their HCP had discussed at the time of their diagnosis such as: what to expect during pregnancy, symptom dormancy during pregnancy, what to expect during delivery, and treatment options while trying to conceive. Effective communication between patients and HCPs is crucial to the successful management of MS, and results from this study indicate that there is an unmet need for better-quality family planning counselling for female MS patients. Information from the study was used to prepare information toolkits for HCPs and female MS patients to further aid and improve patient education. Improving patient education and providing better-quality information on the effect of pregnancy on MS will allow female MS patients to make their own well-informed family planning decisions with their HCP. □

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