

## What Are the Support Needs of Men with Multiple Sclerosis, and Are They Being Met?

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**Practice Points**

- The needs of men with MS are different from those of women in terms of psychological factors such as well-being and mental health and support.
- Support groups, as they are conceptualized in a traditional sense, may not be the most appropriate form of service provision for men with MS.
- Health-care professionals need to take into account the needs, desires, and capabilities of those for whom the intervention is targeted so that service development draws on the perspectives of those living with MS.

## Abstract

**Background:** Multiple sclerosis (MS) is a chronic, degenerative condition of the central nervous system that can lead to high levels of disability and a range of psychological and social problems. Although considerable research exists on the experience of living with MS and the disease's psychosocial consequences, much of this has focused on women and has seldom considered the male perspective. It is possible, therefore, that men may differ from women in how they experience MS and the type of support or interventions that meet their needs.

**Methods:** A literature review was undertaken to identify the specific support needs of men with MS, describe current support available to men with MS, and evaluate the extent to which these needs are met by current service provision.

**Results:** The literature reviewed suggests that the needs of men with MS are different from those of women in terms of psychological factors such as well-being and mental health and support.

**Conclusions:** If interventions are to be evidence based, then health-care professionals need to take into account the needs, desires, and capabilities of men with MS to inform service development. Further research is required to explore this, both qualitatively and quantitatively, to address the gaps in the evidence base of support needs for men with MS.

## **INTRODUCTION**

Multiple sclerosis (MS) is a chronic, degenerative condition of the central nervous system that can lead to high levels of disability and a range of psychological and social problems. A recent incidence and prevalence study estimated that there were 126,669 people living with MS in the United Kingdom in 2010, with the disease affecting 91,444 women (72%) and 35,225 men (28%).<sup>1</sup> The complexities of MS require a range of services to ensure that those affected by MS and their families are adequately supported. Although considerable research exists on the experience of living with MS and the disease's psychosocial consequences, much of this has focused on women and has seldom considered the male perspective.<sup>2-4</sup> Research that explores the experiences of men with MS is important, as evidence has consistently highlighted differences in both how men and women view their health and how they use health-care services. It is possible, therefore, that men may differ from women in how they experience MS and the type of support or interventions that meet their needs. This article aims to identify the specific support needs of men with MS, describe current support available to men with MS, and evaluate the extent to which these needs are met by current service provision.

## **GENDER DIFFERENCES IN PERCEPTIONS OF HEALTH AND USE OF HEALTH-CARE SERVICES**

Evidence suggests that men spend less time on their health, and engage in fewer preventative health behaviors (eg, drink more alcohol, smoke tobacco more, have poorer diets), than women.<sup>5</sup> Young men in particular typically disregard health and may not seek help due to perceptions of invulnerability and pressure to demonstrate independence.

Differences between men and women in use of health-care services have also been noted.

Robertson and colleagues<sup>6</sup> found that men, especially those aged between 16 and 44 years,

underused health-care services. Setting was identified as an important factor, with locations such as general practitioner surgeries and children's centers perceived as stereotypically feminine. It is often suggested that barriers to utilizing health-care services are a result of men's socialization to appear tough and resilient.<sup>7</sup> Indeed, research has indicated that men often subscribe to dominant hegemonic masculine ideals of toughness, robustness, and stoicism.<sup>8</sup> This has led to men's health coming to the forefront in various health discourses,<sup>9</sup> including within the context of chronic conditions, such as MS. People affected by MS may often experience a sense of powerlessness and pronounced vulnerability; it is perhaps, as Riessman<sup>10</sup> notes, a "disease that challenges capacities usually associated with [hegemonic] masculinity" (p. 8) and the notion of the male as protector and provider. How men with MS negotiate discourses of masculinity and seeking of support is of particular interest, especially as use of health-care services is typically viewed as weak or feminine. Existing research in this area has focused on biologically male conditions<sup>11</sup> but has not considered those that are constructed as gender neutral or more prevalent in women, such as MS.

### **THE NEEDS OF MEN WITH MS**

The complex challenges associated with encouraging men to use health-care services are of particular relevance to those affected by MS. Living with chronic, debilitating health conditions can often result in a variety of negative psychological consequences, including depression<sup>3,4</sup> and low self-efficacy,<sup>12</sup> in addition to having a negative impact on existing relationships.<sup>13</sup> One study<sup>12</sup> found distinct gender differences in self-efficacy of people with MS; women had a significantly greater belief in their ability to function with MS than men, although no significant differences were found in belief in ability to control MS. The findings also identified that men with progressive forms held poorer beliefs in their ability to control their MS and function with it than those with relapsing-remitting MS (RRMS). Individuals

with MS could therefore benefit from interventions that enhance self-efficacy—for example, providing skills for self-management of MS, offering education and support for the patient and family, introducing the patient to others with MS who could act as mentors, encouraging physical reconditioning, or referring to a support group that will meet individual needs.<sup>12</sup>

Furthermore, a large-scale study using the Web Portal of the UK MS Register<sup>4</sup> identified that anxiety and depression are highly prevalent in people with MS, indicating that their mental health needs could be better addressed. While women suffered higher levels of anxiety than men, conversely men were found to be more depressed than women, especially men with RRMS.<sup>4</sup> Although women may experience a need for psychosocial support to a greater extent than men,<sup>14</sup> it is plausible that men, and particularly younger males with MS, may be less likely to express and seek support than their female counterparts.

Other studies have indicated that health-related quality of life (HRQOL) is worse in people with MS compared with other chronic conditions<sup>15,16</sup> and that there are important gender differences in HRQOL scores.<sup>17,18</sup> Casetta and colleagues<sup>17</sup> found that the impact of disability, measured using the Expanded Disability Status Scale (EDSS), on HRQOL scores was higher for men than women on a number of subscales, including physical functioning, vitality, social functioning, emotional well-being, and mental health, concluding that MS affects HRQOL in all its dimensions. Therefore, despite severe physical impairment, women with MS appeared to maintain psychological and mental well-being to a greater extent than men, which may indicate differences in psychological coping and adjustment strategies used by men and women. As the prognosis for men with MS is typically worse than for women<sup>19</sup> and disability appears to have more of an impact on HRQOL in men, it is possible that the impact of MS on HRQOL could be reduced through interventions that are aimed at coping with the disease, for example, increased psychological support in rehabilitation programs. Overall, therefore, evidence suggests that people with MS may have significant psychosocial

issues with which to contend and that there may be psychological morbidity associated with MS, along with reduced HRQOL.

### **CURRENT SUPPORT FOR MEN WITH MS: ARE THE NEEDS OF MEN WITH MS BEING MET?**

Despite these well-documented concerns of men with MS, how men obtain information or support in times of need and the development of support services for men with MS has received very little attention in the academic literature, which has predominantly focused on the provision of support groups.<sup>20,21,26</sup> There is evidence to suggest that support groups can offer individuals a strong support mechanism, which has been demonstrated in a number of long-term conditions, including MS.<sup>2,22</sup> Support groups can also significantly reduce symptoms of psychological distress by promoting a sense of normalization through contact with others in a similar situation<sup>2</sup> and have been linked to improved mental health.<sup>23-</sup><sup>25</sup> Indeed, detailed information about support groups for people with MS is provided via MS organizations such as the MS Society and MS-UK. Furthermore, research<sup>26</sup> has found that patients with poorer QOL and greater levels of depression did show improvements on these respective measures; those with better mental health functioning may be at risk for deterioration in support groups as a result of upward and downward social comparison. Therefore, men may benefit from support groups, as they typically have poorer HRQOL than women.<sup>17,18</sup> However, while researchers and clinicians have advocated support groups as a way of improving psychological well-being,<sup>21</sup> there is a paucity of evidence that social support interventions can improve the quality of life for men with MS.

Indeed, one reason why support groups do not necessitate psychological improvement in people with MS may be because they do not meet the needs of the participants.<sup>26</sup> While many patients do require some form of social support, this is not likely to be met through

limited meetings with others with MS. Indeed, a recent study<sup>29</sup> concluded that improved well-being is associated with the level of subjective identification with a support group rather than support group membership per se. Therefore, while effort should be made to encourage men with MS to engage with support groups, this must be done in a way that promotes a sense of belonging and commonality with other group members rather than focusing on attendance. Nevertheless, the characteristics of those who attend support groups and reasons for nonattendance at support groups are poorly understood. Indeed, only two studies have addressed these issues directly, and these predominantly focused on women, particularly married, middle-aged or older adults.<sup>28,29</sup> In a study exploring attendance and perceived helpfulness of MS support groups in England and Scotland,<sup>28</sup> findings suggested that individuals were more likely to attend a meeting if they were aged 45 to 64 years, if they had been in contact with a health professional in the last 12 months, and if they felt they had the ability and means to access MS-related information. In addition, only 43% attended a support group since diagnosis, and many reported that such meetings were not helpful. More recently<sup>29</sup> it has been suggested that women with MS were more likely to seek social support than men but were also more likely to wish that things were different. Women may also be more likely to accept the condition and adopt coping strategies to assist them in living a productive life, for example, attendance at support group meetings. Indeed, differences in support group attendance have been noted. Finlayson and colleagues<sup>30</sup> reported that women were 1.56 times more likely to attend a support group than men. Similarly, others have concluded that while men were less likely to attend group treatment sessions than women, no other variables were associated with nonattendance.<sup>31</sup> Since attendance rates influence the effectiveness of interventions, reasons for nonattendance at support group sessions need to be determined.



## **IMPLICATIONS FOR RESEARCH**

Support groups, as they are conceptualized in a traditional sense, may not be the most appropriate form of service provision for men with MS. If interventions are to be evidence based, then health-care professionals need to take into account the needs, desires, and capabilities of those for whom the intervention is targeted so that service development draws on the perspectives of those living with MS.<sup>31</sup> There is a need to listen to the voices of men and ensure that their voices are clearly heard so health-care professionals can be responsive and sensitive to the needs of their clients.<sup>31</sup> There is also a need to educate men about support groups and destigmatize the decision to seek support while recognizing that support groups may also need to be tailored so that men feel able to attend. At present, there is a dearth of evidence that clearly points to the support needs of men with MS and how men with MS can be supported. For example, why are men less likely to attend support groups than women? Is this because they do not perceive such groups to meet their needs? Further research is required to explore these questions, both qualitatively and quantitatively, to address the gaps in the evidence base of support needs for men with MS. This could be achieved using in-depth qualitative methods that focus on the lived experience of men with MS in addition to large-scale quantitative studies that utilize existing resources such as the Web Portal of the UK MS Register. In doing so, the evidence base for what works in terms of support for men with MS would be greatly enhanced.

## **CONCLUSION**

This article has identified that the needs of men with MS are different from those of women in terms of psychological factors such as well-being and mental health and support. While clinically significant symptoms common to men and women with MS can be treated in a similar fashion—for example, through support groups—little is known about whether these

are effective for both groups. Any intervention or program must take into account the type of support that could be presented to men and consider that for some masculinity may be more important than seeking support.<sup>32</sup> As the prognosis for men with MS is typically worse than for women<sup>19</sup> and disability appears to have more of an impact on HRQOL in men, it is possible that the impact of MS on HRQOL could be reduced through strategies that seek to educate men or destigmatize the decision to seek support—for example, interventions that enhance self-efficacy by providing skills for self-management of MS, offering education and support, introducing the patient to others with MS who could act as mentors, and encouraging physical reconditioning. Thus, the support group may be beneficial for men; however, such groups need to be tailored appropriately so that men feel able to attend. The key characteristics of those who do and do not attend support group meetings have received little attention, and research that has addressed these concerns has not considered the male perspective. While it is important that services and interventions to support men with MS do not reinforce dominant stereotypes or encourage greater use through the development of “male friendly or gender specific” programs,<sup>7</sup> to truly engage in evidence-based practice, the needs of those targeted by interventions must be considered to develop appropriate services that enhance quality of life for men living with MS.

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