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Title: Social capital components and social support of persons with multiple sclerosis: a systematic review of the literature from 2000 to 2018.

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Abstract

Purpose: To identify experiences of persons with multiple sclerosis (MS) in terms of social capital and its components (i.e. social networks, trust, and interpersonal relationships) and social support based on the current scientific knowledge.

Methods: Systematic literature review was conducted through PubMed, Scopus, Web of Science, ProQuest, and PsycINFO. Included articles were published from 2000 to 2018 and met specific selection criteria. Screening of records determined eligible studies for inclusion to data extraction and synthesis process.

Results: A total of 551 abstracts were screened, of which 34 studies met all selection criteria. The themes that emerged referred to the impact of physical and cognitive impairments on social functioning, stigma, psychosocial, emotional and mental challenges, association of quality of life with social capital components and social support, and contribution of social support to improvement of social functioning and health of persons with MS. Persons with MS face a series of issues regarding social support and social capital-related components, primarily facing psychological difficulties, difficulties with making and maintaining interpersonal relationships, and limitations for participating in social and daily activities due to the symptoms of MS, particularly fatigue.

Conclusion: It appears that the ability to seek and maintain social relationships and to participate in social and daily activities is important for persons with MS. This has an impact on their quality of life, as well as on their health functioning, however issues around mobility and stigmatisation of their condition hinder their social functioning.

Keywords (MeSH terms): *Social Capital; Social Networks; Social Support;Multiple Sclerosis; Review Literature.*

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1. Introduction

Currently, the health of the global population is in a state of transition, as ageing and chronic diseases are increasing, along with the so-called 'compression of morbidity'. The European population, in particular, faces an unprecedented ageing process, given the increased life expectancy in combination with reduced fertility rates, while by the year 2050 persons over 60 years old are expected to represent more than one fifth of the overall population [1] [2]. Increased life expectancy leads to a higher frequency of non-communicable diseases and to a subsequent increase on the burden associated with these conditions [3] [2]. Among chronic conditions, neurological conditions represent the highest burden in terms of years lived with disability as reported by the Global Burden of Diseases [3]. Regarding multiple sclerosis (MS) in particular, it has been found that complexity and multidimensionality exist in the daily lives of people living with this condition [4]. It has been also argued that functioning and disability of persons with MS can only be understood by considering environmental and personal factors [4]. Moreover, the World Health Organization [5] has acknowledged social barriers, such as social stigma, and the detrimental consequences these issues may have on health and well-being, including functioning restrictions pertaining social participation and social relationships. Social isolation has been identified as a strong determinant of poor health and neurological changes, and it has been argued that since social networks influence health, mapping and monitoring social networks of neurology patients can be utilised for therapeutic purposes by health professionals whilst simultaneously improving understanding of their health behaviours and create sustainable change in their lives [6]. Consequently, the identification of factors influencing social relationships of persons with MS could also improve their health and well-being. Notions relevant to social relationships include social capital and social support.

In the current study, social support is defined as the extent to which a person views her/his social relationships as available to provide assistance if needed [7]. Social support – although based on reciprocity within social networks – is not treated here as a component of social capital, since personal networks have been distinct from social support research [6], although there are studies that treat social support as a component/indicator of social capital. In particular, it has been pointed out by a recent study [8] that current knowledge of the effect of the various dimensions of social relationships (such as quality and quantity of social relationships) on health is limited, given the lack of a consistent terminology. For example,

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several studies define social support as part of social networks, while others consider social networks and social support as two distinct dimensions of social relationships [8] [9].

House and Kahn [9] defined social network as the structural dimension of social relationships, encompassing aspects such as size, density, reciprocity, frequency, and homogeneity [9]. In other words, social support studies commonly assess the quality or quantity of a person's social ties, whereas social network studies explore the interrelationships between ties by focusing explicitly on the specific network links [10]. Social capital includes social networks, which have been defined as the ties of persons within social groups [11] and constitute the structural dimension of social capital [12] [13]. Social networks can be distinguished into formal and informal networks, with formal networks including ties within political, religious, and other organised groups, whereas informal networks ties among friends, neighbours, etc. It has also been claimed that there is a cognitive dimension of social capital including trust towards people in general, trust in institutions, as well as social norms [14]. According to Putnam [15], social capital refers to features of social organisation, such as social networks, norms, and social trust, which enable coordination and collaboration between people. Social capital and its components (i.e. social networks, interpersonal trust and compliance to civic norms) have been found to be positively associated with good health status and psychological well-being [16] [17] [18] [19]. Thus, enhancement of social capital and its components could potentially contribute to the improvement of the experiences also of persons with MS beyond diagnosis and avoid further deterioration to their health due to psychological issues caused by the existing social barriers, which hinder social participation and received support.

The aim of this study is to identify the experiences of persons with MS in terms of social capital and its components (i.e. social networks, trust, and interpersonal relationships) and received social support, based on current scientific knowledge. The main objective is to report on the main issues persons with MS face in respect to their social capital and received social support and the suggestions of scientific studies for improving the experiences of persons living with MS in relation to these issues.

2. Materials and methods

The methods used in this study are that of a systematic literature review. A literature review (or research synthesis), is conducted by selecting documents that include data/ideas relevant to the exploration of views on the topics of interest, as well as evaluating these documents

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[20]. The 'PRISMA 2009' checklist [21] has been used here as a guide in order to conduct a systematic literature review. The guidelines of the PRISMA checklist include that authors in systematic reviews should record all results of the process of data collection and analysis, thus the availability of protocols to readers and records of all the steps followed can allow readers to identify any deviation from stated methods and whether there is any bias on the results of the review and their subsequent interpretation [21]. Therefore, the search protocol and archives of all the steps taken in this study regarding search, selection, and analysis of eligible studies are available upon request.

The search stage of the literature review has been conducted using the following databases: PubMed, Scopus, Web of Science (Core Collection), ProQuest (Social Science Premium Collection), and PsycINFO. Articles were identified that were published from January 2000 to August 2018 in peer-reviewed journals, were written in English, and explicitly explored social support and/or social capital and its components, such as social networks or social relationships or interpersonal relationships/networks or trust of persons with multiple MS. The combinations of search terms applied in the abovementioned databases were: 'social capital' OR 'social network*' OR 'interpersonal relation*' OR 'interpersonal network*' OR 'trust' OR 'social support network*' AND 'multiple sclerosis'.

2.1 Selection criteria

The selection criteria were developed in order to capture all studies of interest and were as broad as possible to avoid any selection bias. No limit was applied regarding publication type (e.g. original research, commentary, etc.) to avoid publication bias. However, based on the aim of this study, selected papers should report original findings on experiences of persons/participants with MS, thus only empirical research evidence was considered. Conference proceedings were excluded, along with studies of which the abstract or full text was not available to the researcher.

The following inclusion and exclusion criteria were set prior to search in databases and during abstract screening, to facilitate the selection process based on the aim of the study:

2.1.1 Inclusion criteria

1) Empirical studies published in peer-reviewed scientific journals
2) Publications in English language
3) Published from January 2000-August 2018

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4) Publications concerning any country, state, city, or village, at local, national or international level
5) Publications concerning self-reported data of adult (18+) human participants-patients (not included studies reporting only data from caregivers, health professionals, parents, teachers, or other proxies)
6) Publications including the search terms in their Title-Abstract-Keywords or Title/Abstract or Topic.

2.1.2 Exclusion criteria

1) Conference proceedings
2) Books and book reviews
3) Theses/Dissertations
4) Interviews
5) Scientific articles which did not report basic information on both methodology and findings of each empirical research (such as cases of commentaries or editorials)
6) Other non-peer-reviewed sources (such as project reports, national guidelines, film reviews, etc.)
7) The study focused only on one specific type of relationship (e.g. patient-spouse, patient-doctor or patient-caregiver relationships)
8) In the full text of the study there was no empirical research methods and findings described, with participants with MS.

2.2 Screening of records

The initial phase of the screening process of the review included the screening of abstracts for eligibility of studies for inclusion based on the aim of this study. In cases where the title of a paper appeared to be relevant, but the abstract was missing or it was unclear whether the study referred to MS and social capital components in question, the paper was directly included in the next step (i.e. screening of full text). In cases where the full text was not available, then the paper was not included. The next screening phase included the screening of the full text of the papers in cases where the abstract or title was considered relevant to the aim of this study. During the screening of full texts, the full text of each selected paper was read thoroughly to ensure it met the criteria for inclusion and the following information was recorded: the decision of inclusion or exclusion for further analysis and the respective reason for inclusion or exclusion. Apart from the main exclusion criteria mentioned above, a large

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number of studies were excluded due to the following reasons: presenting neuroscience/genetics tests or experiments in relation to brain structure/function/neuroimaging or medications; assessing the impact of online interactions or support via web-based/internet social networking sites (e.g. chat forums and Facebook); describing or assessing the impact of a specific implemented programme/intervention/workshop etc.; or presenting the design of a programme/intervention without any findings. Additionally, during the screening of full texts the references section of each included paper was read in order to identify additional potentially relevant studies, which had not been already retrieved through the databases' search.

2.3 Data extraction and synthesis

The outcome of the screening of full texts was the final list of selected studies deemed eligible for further qualitative analysis. On the selected studies, data extraction and synthesis were performed based on the principles of thematic analysis. Literature review can undergo open coding, based on grounded theory [22]. Thematic analysis derives from the principles of grounded theory and is conducted through open coding, meaning that the text segments relevant to the topics explored are divided in an analytical manner under categories and in this manner form blocks of concepts [23]. Text segments can be paragraphs, phrases or words containing key concepts relevant to the topic and themes are patterns of meaning found in the text segments of the data collected [24]. In the current study the coding was performed on the latent level, meaning that themes were considered based more on the meaning of text segments than on specific words or terms these segments included [24].

More specifically, data synthesis of pre-defined themes – decided among authors based on the aim of this study – were used for data extraction. Consequently, texts segments were extracted from each included study, providing the following information: a) author(s); b) year of publication; c) journal published; d) aim(s) of study; e) site of study; f) sample size; g) age of participants; h) inclusion criteria; i) method of data collection (including method of recruitment of participants); j) specific measures/instruments used for assessing social capital components and/or social support; k) main findings in relation to social capital components and/or social support.

The data synthesis of the extracted data followed, in a systematic and comprehensive manner, based on the frequency and/or patterns across studies' reported information. However, the data extracted on the main findings from the selected studies in relation to social capital components and/or social support, a more in-depth thematic analysis was

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performed without the use of pre-defined themes, given the large amount of the extracted data on this part. Thus, the extracted text segments on main findings from studies were coded under themes of meaning, based on patterns of meaning and frequency of their appearance in text.

The screening of abstracts and full texts and the coding process during data extraction and synthesis was initially performed by one of the authors and then controlled independently by the two other authors. The inclusion of studies for data extraction and synthesis had to pass the unanimous agreement of all the authors. For the representation of the steps followed during the systematic review process, the 'PRISMA Flow Diagram' [21] has been used, which is an established tool for systematic literature reviews' representation (figure 1).

3. Results

The search of the abovementioned databases of peer-reviewed publications yielded 551 records (figure 1).

<figure 1 should appear here>

After duplicates were removed, the abstract of each of the 332 records was screened for eligibility for inclusion in the current study, based on the selection criteria mentioned above. The abstracts' screening led to 58 selected articles, of which the full text was read thoroughly to determine eligibility for final inclusion. Finally, 34 studies were considered eligible for further qualitative analysis.

3.1 Publication information, sample characteristics, aims, and data collection methods of selected studies

Table 1 presents the list of the selected studies including the sample size and assessment techniques of each study.

<table 1 should appear here>

Below the main findings from the extracted data of the selected studies are presented per pre-defined theme.

Regarding **year of publication**, only one of the studies was published before 2004, while 59% of the selected studies were published between 2010 and 2018. Moreover, seven

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of the included articles were published at the Disability and Rehabilitation **journal**, two at the Chronic Illness journal, two at the Quality of Life Research journal, and the rest of the 23 studies were published with other peer-reviewed journals. In terms of **countries** where the studies were conducted in, 14 out of the 34 studies were conducted in the United States of America (USA), three in Italy, three in Poland, three in the United Kingdom, and two studies were conducted in each of the following countries: Canada, Germany, Iran, Norway, and Spain; while some were conducted in more than one country.

The **sample size** across studies varied significantly from eight to 1,372 participants. The average **age** of participants (unweighted) in total was approximately 48, with high variance observed across studies on the age of participants; ranging from 18 to 96 years old.

The **main aims** of the selected studies were also varied, with the majority of the studies aiming to explore aspects of social functioning and/or social support, in order to discern facilitating or hindering indicators particularly regarding interpersonal relationships, social participation, social inclusion, social stigma, and quality of life, with almost all of the studies investigating social activities of persons with MS, and some of them focusing on the association of MS with loneliness, health-promoting behaviour, as well as stress management.

The selected studies showed a variety of **data collection methods**, mainly quantitative, but also qualitative, using primary or secondary sources and various recruitment methods. Four of the selected studies used longitudinal data [25] [26] [27] [28] and one of them was a prospective study [28]. Most studies used more than one instrument for assessment, mainly social support, quality of life, health promotion, and/or social functioning questionnaires or items, with few of these tools having been designed specifically for persons with MS (e.g. the Multiple Sclerosis Quality of Life (MSQoL)-54 questionnaire). Four of the selected studies used the Health-Promoting Lifestyle Profile II (HPLP II), three the MSQoL-54 questionnaire, and two the Medical Outcomes Study Modified Social Support Scale (MSSS), whereas the questionnaires used by the rest of the quantitative selected studies for assessing social relationships varied greatly. Most items used in the selected studies explored the social and emotional support received by persons with MS, their everyday social activities/participation, and particularly the impact MS had on their social life. Only one of the studies used an instrument focusing on the assessment of social capital *per se* (i.e. the World Bank's Social Capital Integrated Questionnaire). From the components of social capital, social networks/relationships were the most explored, whereas only two of the studies

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explored trust. Quality of life, loneliness and depression were also assessed in terms of social connectedness and potential barriers/challenges that persons with MS experience.

3.2 Themes of main findings of selected studies

Regarding the thematic analysis performed on the selected studies' main findings, table 2 presents the themes that emerged, followed by a detailed presentation of each of these themes.

<table 2 should appear here>

3.2.1 Impact of physical and cognitive impairments and physical and social environmental barriers on social functioning

Stigmatisation, social exclusion, and environmental barriers, including restricted mobility have been found as determinants of psychological difficulties in persons with MS [29]. Persons with MS have reported that their greatest difficulty is getting around, that they have reduced functioning in terms of life activities due to their disability and difficulty in social participation [30] [31]. The most difficult areas of participation for persons with MS are barriers in the world around them (54.4%) and drain on financial resources (41.7%) [30], with men reporting financial problems due to MS more than women [32]. However, the barriers reported in the study by Gallagher and Mulvany [30] were not specific in regards to whether they were social and/or environmental barriers. Nevertheless, socialization remains important, but may be complicated for persons with MS since it is a disease with elusive symptoms and fluctuating nature [33]. Fatigue is an aspect of MS that some of the selected studies explored in relation to social functioning and/or quality of life [31] [34] [28] [35]. The fatigue persons with MS experience due to their disease makes their social interactions difficult and given that others do not adequately understand this fatigue – not even medical workers – persons with MS deal with it without any support from other people [34]. Similarly, fatigue has been reported as the most troubling symptom having great physical, psychological and social impact on the person with MS, and all participants of the specific study indicated that fatigue is the symptom that affects almost all aspects of their lives [35].

According to the qualitative study of Tabuteau-Harrison et al. [36], three main themes encompass the different social processes that persons with MS experience in terms of adjustment to living with MS: 'loss and change in social roles and relationships'; 'social

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participation as distraction'; and 'engaging with or avoiding others'. 'Loss and change in social roles and relationships' included issues persons with MS face in terms of interpersonal relationships, such as losing parts of yourself with the loss of a wide range of function and self-care ability [36]. Changes in family relationships is another issue persons with MS face, including loss in their marriage or increasing support by family members who assist them in everyday tasks [36]. Persons with MS can also experience changes in friendships, with some of them losing old friends, others being able to keep general friendships, but those with challenged adjustment to living with MS mainly experience difficulty in maintaining friendship networks [36]. Apart from changes in friendship networks, persons with MS also face changes in wider social networks within society, acknowledging the social stigma of MS and the ignorance of the public about MS symptoms [36]. The theme of 'social participation as distraction' included issues pertaining barriers to participation and benefits of active participation, with participants stressing ways through which their social networks provided a positive distraction for them from thinking about the downside of MS [36]. The other main theme that emerged was 'engaging with, or avoiding others', which included issues relevant to experiences of group engagement and group avoidance, for example, as most of them stated they benefit from friends that do not have MS, and therefore avoided engaging with MS groups [36]. Overall, according to the same source [36], all persons with MS have experienced changes in relationships and loss across a range of their social networks, and together with changes in empathy and support from those close to them, had a marked impact on their ability to cope with the consequences of their health condition. Similarly, it has been reported elsewhere that persons with MS face changes in values and beliefs, changes in relationships, and identification with others, in particular regarding those who are closest to them who may also take on the role of caregiver for them, as well as changes in how persons with MS perceive themselves and their perceptions of how they are viewed by others [35]. Based on the same source, relationships with others, family and friends and – in some cases – a spiritual higher power, appeared to be important for helping them to adjust to the disease and the uncertainty of life with MS [35].

Persons with MS have been also found to experience lack of autonomy since 39% of them also experience severe difficulty in doing things for themselves, whether it is for relaxation or pleasure [30]. Also, more than one third (38.2%) of persons with MS spend a lot of their time dealing with the physical aspect of disability or its consequences, while 34.5% of persons with MS report that their family also experience severe difficulties due to their disability [30]. The existence of even a mild disability has negative impact on social

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functioning for persons with MS [28], with those with mild-to-moderate MS often being able to have a social life if they pushed themselves [34]. On the other hand, in the study of D'hooghe et al. [37] on the association between health promotion behaviour and disability progression in MS, no associations were found regarding stress management and interpersonal relationships, and concluded that changing health promotion behavior could not lead to reduced disability progression for persons with MS. Nevertheless, in the study of Zhang et al. [27] it was found that social support was a significant predictor of health promotion behavior and quality of life. Achievement of desired roles in work and relationships for persons with MS often involved reduced levels of participation [29]. Furthermore, it has been reported that there is considerable variability among persons with MS as to how they experience functional limitations [25]. In another study on persons with MS it was found that social support predicted physical activity, while support from friends had a stronger relationship to physical activity than support from family [38].

An unsupportive environment for persons with MS is formed by poor access to social support, lack of information, and limited options [39]. Decrease of social activities and networks of friends for persons with MS has also been identified by another study, especially regarding participants with severe disability [32]. Specifically, only 47% of persons with MS with severe disability stated that they received visits from old friends within the last month prior to the interview, whereas nine out of ten persons with MS with mild disability reported to be in touch with previous friends and colleagues [32]. In fact, functional disability of persons with MS associated with mobility issues and cognitive impairments led to reduced social contacts, job loss, and lower standards of living [32] [36].

Apart from mobility issues, persons with MS may also experience problems with communication or speaking [40], with ease of communication constituting an important dimension of satisfaction of persons with MS in terms of communicative participation [41]. Other dimensions of satisfaction for persons with MS with communicative participation, such as how individuals define success and regarding the personal meaning of communication, do not exist in most relevant instruments [41]. Thus, there are gaps between existing measurement tools and what is actually reported as important from persons with MS with communication difficulties [41].

According to a study conducted in the USA on persons with MS, with ageing comes a series of changes in their social needs, as well as a decrease in social activity and use of community resources, due to the combination of disability resulting from MS with the inaccessibility of services and lack of transportation [39]. Moreover, as they age, persons

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with MS fear that they will become a burden to caregivers and will have to go to a nursing home, due to the growing need for support [39]. Although these changes are common among older adults, persons with MS experience such social changes earlier in their life [39]. Finally, one of the studies focusing on older adults with longstanding MS [27] found that two symptom clusters were highly related to their health promotion behaviors and quality of life, while social support was a significant predictor of all outcomes. These symptom clusters were: physical/psychological/cognitive symptoms and pain symptoms [27]. Accordingly, it was suggested that MS incapacity and social support have a greater influence on the physical activity in older adults with MS compared to younger populations, whilst highlighting the profound impact of social support on health promotion and quality of life for older individuals with MS [27].

3.2.2 Stigma

According to the participants with MS in one of the selected studies, the stigma these people experience is not necessarily a result of discrimination or intention to embarrass persons with MS or make them feel less worthy, but it can be the result of ignoring of overemphasizing MS in social relationships [42]. In other words, when persons with MS form support networks, they consider that these networks should be adequately informed about MS, thus inform these networks (i.e. their relatives and interpersonal relationships) about their MS, their life situation, as well as the social and psychological issues deriving by suffering from MS [42]. Therefore, it requires careful consideration of the social context in order to create a balance between treating the persons with MS as normally as possible and at the same time acknowledging MS and the impact it has on social interaction [42]. According to the findings of a qualitative study, exploring cases of persons with MS and their relatives, the concept of embodiment is important for understanding the illegitimacy of stigma, with participants regarding the sick role both as a resource and a threat to oneself [43]. Persons with MS have also reported to have purposefully informed or concealed MS in order to influence social judgement in social interactions [43]. The reason for this concealment was due to a desire to protect themselves from being deprived of the feeling of social belonging, especially in the work environment [43]. Social exclusion was found to be insufficiently understood in terms of disability as a political and social construction, with the same study suggesting that the body when ill is not just a biological organism with functional loss, but also the center of attention, the medium of expression and knowledge [43].

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3.2.3 Psychosocial, emotional and mental challenges

Women with physical disability due to MS experience depression, with some of the significant predictors of depressive symptoms being pain interference, social support issues, and recent abuse, therefore these factors should be addressed in order to tackle depression [44]. For women with MS, loneliness is mostly reported by those who are unmarried, have lower levels of social support, greater functional limitation, lower level of subjective health status, and greater social demands of illness [45]. However, both these studies [44] [45] focused only on women with MS. According to another study on both male and female participants with MS, it was found that depressed mood was in fact four times more frequent in men than in women [32]. One of the selected studies argued that considering the high rates of refractory depression of men and women with MS, special attention to this issue should be provided to this specific population [46]. For persons with MS, depression has been found to be associated with social activities, such as interacting or maintaining connections with friends, intimate relationships, and children [31]. Depression and anxiety have been found to be common among not only persons with MS themselves but also their relatives [32]. One of the studies also found that there is an additional physical and psychosocial impact of MS in terms of adaptation and adjustment for the individual with MS. There is reported denial as well as initial concealment of the diagnosis and diminished confidence, thus persons with MS may face issues of self-concept and identity [35].

According to one of the included studies exploring disability friendship networks' associations with subjective well-being, nearly half of participants (43%) with physical disabilities – including persons with MS – do not have friends with any physical disability, while less than half have a close friend with the same diagnosis as theirs [26]. Specifically, participants with MS reported having a mean of 1.12 (SD=2.19) of close friends with MS, and a mean of 2.06 (SD=3.22) of close friends with physical disability due to other pathologies [26], thus having overall small within- and cross-disability friendship networks. Based on the same source, persons who share a disability diagnosis also reported higher quality of life and social role satisfaction, while these effects were maintained for cross-disability friendships too, thus indicating that the benefits of friendship may relate to a shared sense of the experience of disability, than to sharing a specific diagnosis [26]. Moreover, women with physical disability appear to have overall more cross-disability friends than men, while a statistically significant association between age and cross-disability network size was found too, with increasing age being associated with more friends with physical disability

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[26]. Greater global perceived support has been associated with less depression for persons with MS, with those having more positive social interactions, emotional/informational support, and affectionate support also reporting fewer symptoms of depression [47], while those with greater interpersonal problems self-reported poorer outcomes of treatment of depression [46]. It is generally accepted that the emotional state of a person is the most important aspect of her/his quality of life, therefore both the early recognition and management of depression and anxiety symptoms are very important [32].

In a study exploring benefit finding – meaning the benefit or gain a person with medical problems finds from her/his adversity – of persons with MS in a stress and coping framework, it was found that benefit finding plays an important role in maintaining a positive psychological state for persons with MS, especially in the area of family relations, but has less influence on regulating distress for them [48]. Psychosocial difficulties for persons with MS, which effect the attainment of desired roles regarding work and relationships, often include fear, uncertainty and frustration [29]. In general, psychosocial difficulties experienced by persons with MS are related to interpersonal relationships, community life, recreation and leisure [40]. Statistically significant relationships have been found among social functioning, role participation (emotional aspects), health-related quality of life (mental aspects), involvement in spiritual growth experiences (i.e. having goals and a purpose in life, contentment, personal growth challenges, and a connection to a force greater than oneself), and maintenance of meaningful interpersonal relations [33]. In other words, these health-promoting practices have been found to be related to less limitation in participation to work and other daily activities, and to mental health, with the frequency of engaging in positive interpersonal relationships being related to increased role participation [33].

It has been found that the mental state of participants who belonged to a healthy control group was better compared to participants with MS [49], with other studies finding that those with MS cope with loneliness in a significantly different way from persons of the general population [50], thus the experience of loneliness for persons with MS differs qualitatively from that of the general population [51]. More specifically, when compared experiences of persons with MS, cancer, and healthier group in a study on loneliness, it was found that persons with MS had the lowest mean score for subscales of emotional distress, social inadequacy and alienation, interpersonal isolation, and self-alienation, whereas healthier participants had the highest mean subscale scores for emotional distress, social inadequacy and alienation, and interpersonal isolation [51]. This probably occurred because persons with chronic illness may have had the opportunity to gather the necessary resources

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for them to deal with illness and loneliness since the onset of their illness, and may consider that feelings of social isolation and lack of intimate relationships are therefore consequences of their illness, whereas healthier persons may simply attribute these same feelings to loneliness [51].

Additionally, it has been found that persons with MS did not have external resources that could reduce stress, nor the ability to use social support when they were under stress [49]. The findings of the same study indicated a clear link between psychosocial factors and pathogenesis of MS, thus suggesting that important or sustained negative life events may be responsible for the pathogenesis of MS [49]. Particularly, persons who lacked social support or had low utilization of social support were found to experience intense psychological stress, which in turn resulted in immune responses and maybe to the onset of MS [49]. According to the same source, psychosocial factors are closely connected to the pathogenesis, pathophysiology and clinical symptoms of MS [49]. Therefore, the necessity for the consideration of psychosocial factors for persons with MS and – in general – the use of the approach of the biopsychosocial model is apparent, given that the biomedical model alone cannot provide satisfactory explanations for the recorded impact of psychosocial factors on health and illness [49]. For persons with MS the experience of ageing might include loneliness and isolation, with persons with MS being at greater risk compared to other older adults, in terms of emotional health issues, role transitions, changes in social relationships, and increasing problems of accessibility of the environment [39].

Moreover, it has been found that individuals with MS who report regular social participation in person with friends have better emotional health compared to those who do not report regular in-personal social participation with friends [52]. Based on the same study, there appears to be no relationship between emotional health and online participation for persons with MS with mean age 59.21 (SD = 9.54) [52]. However, social participation through interacting with friends or the community in person was reported by 67.9% and 46.5% of the participants in this study respectively, while more participants (i.e. 79.9% and 64.4% respectively) reported interacting with friends and community online [52].

3.2.4 Association of quality of life with social capital components and social support

Only one of the included studies aimed to explore the relationship between social capital *per se* and quality of life for persons with MS, finding that the highest average scores of social capital were reported by persons with MS for the dimensions of ‘groups and networks’ and

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‘social cohesion and inclusion’, whereas the lowest scores were reported by persons with MS for ‘trust and solidarity’ and ‘empowerment and political action’ [53]. The same study found a positive and statistically significant relation between social capital and quality of life, concluding that the enhancement of social capital could lead to the enhancement of quality of life in persons with MS, and *vice versa* [53].

Based on the study of Costa et al. [54] on persons with MS, there are statistically significant positive correlations between social support network composition, social group membership, participation in voluntary work, engaging in group sports activities and the physical and health dimensions of health-related quality of life. Particularly, in terms of informal social support networks, 10% of persons with MS did not have a family member to talk to about almost everything, and 21.3% reported that could not trust their friends, however, 74.75% could rely on one or more friends to talk with about everything. In terms of formal social networks, the vast majority of participants (more than 70%) reported to have not participated in sports groups, meetings or voluntary work [54]. Regarding the relationship between social support networks and health-related quality of life it was found that there is a statistically significant correlation between the mental dimension of health-related quality of life and the number of relatives and friends, along with participation in sports groups, meetings, and volunteer work [54]. The same correlation was found for the physical dimension of health-related quality of life, apart from the question of the number of friends a person can rely on to talk with about almost everything [54]. Thus, it appears that when someone with MS has friends correlates with the psychological dimension of their health-related quality of life, and does not correlate with the physical dimension of their health-related quality of life [54]. Furthermore, social support has been found to be a protective factor for quality of life for persons with MS, helping to moderate stress whilst coping with the disease, with the emotional status being the predominant predictor of quality of life [55] and social support being found to also positively influence health promotion behaviour and quality of life of older adults with longstanding MS [27]. In terms of support groups, schemes of companionship run by voluntary organizations can help persons with MS and their families reduce social isolation and thus improve their quality of life [32]. Similarly, nurses and other health providers should consider the impact of both functional impairments and limited social support for promoting health and quality of life for persons with MS, and seek ways to enhance social support for them, for example through community activities, support groups, and follow-up communication [27].

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3.2.5 Contribution of social support and social participation to improvement of social functioning and health

Friendship networks among persons who have physical disabilities have been suggested as adaptive for well-being, therefore should also be promoted in relevant community programmes [26]. Facilitators of social functioning for persons with MS have been found to include support from friends and/or spouses and formal support groups [29]. It has been argued that cognitive reserve could help persons with MS maintain their social interactions, while it is important to monitor patient-centered outcomes in MS management [28]. Similarly, for improving emotional health of persons with MS, it has been suggested that there could be policies and projects implemented which encourage in-person interactions with friends more than online interactions, since it has been found that in-person interactions are more important than online interactions for the emotional health of persons with MS [52]. In addition, there are key factors which influence the rehabilitation potential of a person with MS, including the person's perception of the disease, self-appraisal and relationships with other people [35]. Therefore, it is suggested that interventions that could help people with MS in the role/identity re-examination and adjustment could include positive asset interventions, such as aiming at encouraging persons with MS to develop new interests, activities and relationships, and by addressing identity issues, healthcare professionals can help them manage the disease and enjoy productive lives [35].

It has been suggested that interventions that help persons with MS enrich the quality of their close relationships could be useful. In this way, they promote shared information, affection, and positive social experiences [47]. Accordingly, specialists should focus on the individual person with MS and her/his social support networks, as important elements of adaptation to disease and health-related quality of life, and encourage individuals to participate in different social groups [54]. This can be achieved through a multidisciplinary team of MS specialists, who can work together to assist the individual to repair her/his social support network that is often affected by the loss of social functions in persons with MS [54]. It may also be beneficial for activity practitioners to adopt a more holistic and multifaceted approach to activity promotion for persons with MS, by not only targeting their family members, but also trying to facilitate increased physical activity participation among people with MS and their extensive social networks, since physical activity for persons with MS seems to be more strongly related to friendship networks than family [38]. Increasing social support is a way persons with MS use to manage the impact of their MS, as they report that

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participating in support groups and exercise classes for persons with MS creates feelings of solidarity and motivation, since they interact with others that also have MS [56]. These peer networks also increase understanding of their health condition for persons with MS when hearing other persons with MS share their experiences, whereas some report that it is difficult for them to spend time with other persons with MS who are experiencing progressing disability [56].

Additionally, the level of social support received as baseline and the satisfaction with this support were found to moderate treatment outcome for persons with MS and depression [57]. Those with higher levels of social support and satisfaction with their support networks were found to particularly demonstrate greater reduction of depressive symptoms when enrolled in telephone-administered Cognitive-Behavioral Therapy (CBT), compared to telephone-administered Emotion-Focused Therapy (EFT) [57]. Consequently, it was suggested that before selecting the approach when treating depression in persons with chronic illness, it may be important to assess the baseline level of social support these persons receive [57]. Similarly, it has been found that the severity of the interpersonal functioning of a person with MS at pretreatment can predict the therapeutic outcome, therefore, the development of procedures to address interpersonal difficulties of persons with MS might be effective [46]. Social groups and interpersonal relationships have been found to play an important role in supporting people in coming to terms with MS and living fulfilled lives [36]. Furthermore, a supportive environment is important especially for persons with MS as they grow older, including an environment that promotes self-management and self-control of their disease, and also provides opportunities for enhancement of social relationships, notably through community resources, such as support groups and appropriate services of transportation [39]. It has also been suggested that professionals working with persons with MS can facilitate their adjustment of living with MS by helping them to access or maintain group memberships instead of leaving them to cope with their own individual resources [36]. Regarding ways to combat depression among women with physical impairments due to MS, enhancing their social networks has been argued to hold potential for intervention, but although literature suggests this both for persons with disabilities and the wider population, the interventions aiming at enhancing social networks and social support are very limited [44]. Similarly, women with MS have been found to report higher scores on the HPLP II instrument regarding ‘interpersonal relationships’, while reporting lower scores on ‘physical activity’- with higher scores indicating more frequent engagement/experiences of relevant behaviours – while there appears to be a statistically significant relationship between social support and

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health promoting behaviours for women with MS [58]. Therefore, it has been suggested that a higher level of social support can improve behaviours that promote health [58]. Moreover, it has been suggested that it is critical to enhance health-promoting behaviours along with other treatments and that health providers should expand emotional, financial, and informational support for women with MS [58]. Lastly, women with physical disabilities are at particular risk of social isolation, therefore more research on this demographic is required [44].

4. Discussion

This systematic literature review provided an up-to-date exploration of the issues persons with MS face in terms of social capital components and social support, as well as any suggestions by scientific studies for improving the experiences of persons living with MS in relation to these issues. According to these results, more than half of the 34 studies included in the qualitative analysis were published after 2010, indicating an increasing research interest on this topic. Most of the included studies were published in USA, followed by Italy, Poland and the United Kingdom, with only seven of the studies having been published outside USA and European countries; indicating possibly that more research should focus on these issues internationally. Sample size and age of participants varied across studies. There was a variety of aims of the selected studies, with topics relevant to aspects of social relationships, social functioning and other psychosocial issues. In terms of methodology used by the studies, the vast majority of them applied quantitative methodology, with the use of questionnaires or surveys, whereas qualitative studies, primarily using interviews, were less common. Most studies measured quality of life and/or health promoting behaviours together with aspects of social capital and/or social support, while only one study focused on social capital as such.

The results of the thematic analysis indicated that persons with MS face a series of issues regarding social support and social capital-related components, primarily facing psychological difficulties, difficulties with making and maintaining interpersonal relationships, and limitations for participating in social and daily activities due to the symptoms of MS, particularly fatigue. The themes that emerged illustrated the impact of physical and cognitive impairments on social functioning, stigmatisation, psychosocial, emotional and mental challenges, association of quality of life with social capital components and social support, and contribution of social support to improvement of social functioning

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and health of persons with MS. The social capital components, social support and relevant aspects of the social lives of persons with MS were found to have been mostly explored by the selected studies in relation to quality of life, either as components of quality of life or in association or comparison with participants' quality of life. In terms of components of social capital, apart from difficulties experienced in respect to social networks, persons with MS were found to show lower trust towards people in general. Overall, it is clearly observed that there is a lack of studies focusing on social capital per se regarding MS, while trust was not a common aspect explored by the selected studies; though high levels of social participation, social networks, trust and reciprocity have been found to be associated with good self-rated health [16].

The selected studies have reported on psychological issues as determinants of physical or social functioning, influenced mainly by mobility difficulties, pain, and fatigue due to MS as well as stigmatisation and self-perception issues due to MS. Fatigue and pain have also been found elsewhere to be relevant to body functioning and disability of persons with MS [4]. Particularly, it emerged that physical limitations often led persons with MS to face psychological and social difficulties due to the nature of their condition. The most prevalent of the psychological/emotional challenges persons with MS face seem to be depression and anxiety, loss or difficulties in social and personal/intimate relationships and/or employment, along with fear, uncertainty, loneliness, isolation, and frustration. According to a previous study on the personal perspective of persons with MS, it has been found that persons with MS reported a wide range of emotions, which included depressive symptoms and anxiety [4], – something that is also confirmed in this study. Moreover, it has been reported that neurological diseases known to involve social cognitive impairment include MS [59], with social cognitive impairment being related to loneliness, unemployment, poor quality of life, and mental health issues [59], – again all of which have also emerged in this study. The two-way association between quality of life and social relationships and/or participation in activities and community emerged too, and in particular that the emotional and mental dimensions of quality of life seem to be more related to social participation and meaningful social relationships. On the other hand, social support network composition, social group membership, participation in voluntary work, and engaging in group sports activities were mostly found to be positively correlated to the physical and health dimensions of quality of life. Nevertheless, it appeared that when a person with MS has friends, this correlates with the psychological dimension of health-related quality of life, and not with the physical dimension of it [54], but based on another included study it seems that social support

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predicted physical activity, while support from friends had a stronger relationship to physical activity than support from family [38]. Thus, there is contradicting evidence in the selected studies on the role of friendship networks in relation to the physical activity of persons with MS.

Difficulties in social relationships of persons with MS were found to be influenced mostly by psychological and physical symptoms relevant to their health condition (such as fatigue and pain) and perceived social attitudes and barriers for social participation – in terms of community and daily activities or employment settings. Stigmatisation was reported as the result of ignoring of overemphasising MS in social relationships, an issue that could be addressed through more education and information provided to the public on the nature and symptoms of MS, in order to help diminish stigmatisation due to lack of knowledge and understanding of the health condition. Moreover, it emerged that although persons with MS engaged more with friends and communities online and not in person, there was not any relationship between emotional health and online participation, whereas those who had regular social participation in person with their friends reported better emotional health. This finding indicates that in-person engagement with friendship networks was more beneficial for emotional health of persons with MS, compared to engagement in online networks.

Overall, it emerged that enhancement of social relationships can have beneficial impact on experiences of persons with MS. For instance, according to the current findings there is a positive relationship between social support and quality of life [27] [54] [55], the frequency of engaging in positive interpersonal relationships is related to increased role participation [33]; a lack of or low utilization of social support can cause intense psychological stress which can harm health [49]; initiatives of companionship run by organizations or promoting group membership or community engagement can help reduce social isolation and thus improve quality of life [27] [32] [26]; and the severity of a person's pretreatment interpersonal functioning being predictive of the therapeutic outcome [46].

Moreover, it appeared that biopsychosocial approach could be employed by MS specialists to aid persons with MS in overcoming psychosocial issues and enhancing their social functioning, that they may have lost due to MS, such as by encouraging them to become more involved in social activities and local community. Employing a biopsychosocial approach appears even more imperative considering also that the biomedical model alone cannot explain the effects of psychosocial issues on health and illness as well as it appears that physical activity of persons with MS is strongly associated with friendship networks. Persons with MS appeared to face problems related to employment due to their

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condition and concealing their condition from employers to protect the sense of social belonging that remaining in the workplace – or in any other social environment – can bring. The changes that come with ageing also emerged in the current review for persons with MS, since they might experience loneliness and isolation to a greater extent compared to older adults without MS. In addition, older adults with MS might experience more emotional health issues, role transitions, changes in social relationships, and increasing accessibility problems of the environment along with changes in physical capability, social activity, social needs, as well as other changes. However, some of these changes may be attributed to older age in general rather than MS alone, while social support has been reported as having profound impact on health promotion and quality of life of older adults with MS. Apart from age differences, it has been stated that neurological conditions also have significant differences across and among them – in terms of the complexity of psychosocial issues – given that persons experiencing the same health condition might have different psychosocial difficulties, whereas persons with different health conditions might experience the same psychosocial difficulties [29].

This study has also identified some limitations in the methodology adopted and in the interpretation of findings. The main limitation of this study is that it lacks an assessment of validity of the findings of the eligible studies, as suggested by the PRISMA checklist [21]. To avoid reporting selection bias, the literature review protocol and archives of the selection and synthesis process followed are available upon request. The keywords/terms used in the present database search could have been broader, but the focus of the current study was not on social environment in general, since the study aimed to solely explore aspects relevant to social capital and social support. In addition, one of the limitations was that there was no system employed for recording inter-rater reliability, however, all records of each step of the screening process were made available to the other two authors who controlled them and agreed unanimously on the eligibility of the selected studies for inclusion, as well as the data extraction and synthesis. Another limitation identified was that during the thematic analysis there have been issues observed in studies that overlapped in meaning. For example, psychological and social difficulties were found to be intertwined, however sought to distinguish them for clarity by coding them under two different themes, respectively. Nevertheless, themes might overlap in meaning or results might be repeated if they were eligible for more than one theme. A final limitation of the study is that the country of fieldwork of each of the studies was not considered in the interpretation of results, but the authors did not have sufficient knowledge of potential contextual determinants of each of the

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countries the selected studies were conducted in. Nevertheless, contextual determinants are important to be considered in empirical studies when interpreting results on social relationships, whereas generalisation of results on social networks is not advisable without considering cultural background and social norms of the framework explored.

Future empirical research should also present contextual factors, such as a description of the physical and social environment of the community/country of fieldwork, in order to interpret results on social relationships and social support. There is a tendency for published scientific studies to generalise their results on social networks and social support, however, the informal and formal support providers; the physical environmental and transportation issues people face for social participation; and opportunities for social capital bridging and bonding are not the same in all contexts and should be treated accordingly by studies. The need for exploration of social relationships of persons with MS, behavioural interventions, promotion of social participation in community, enhancement of social networks, trust, and received support was suggested by researchers of the selected studies for improving quality of life of persons with MS. Collecting opinions about the quality of personal interaction, social support and trust in others within the framework of healthcare practice and rehabilitation has yielded consistent evidence of the interaction between MS and social capital, both as a consequence of MS and as an important factor to improve the subsequent quality of life. As it has been argued elsewhere, there is need in clinical practice for a holistic patient-centred approach to care, focusing on assisting persons with MS in developing beneficial coping strategies, as by addressing both their physical and psychosocial needs using non-statutory support groups and other patients as mentors, it could be possible to ease the personal struggle in adjusting to living with MS [60]. Furthermore, one of the main recommendations of the global strategies on non-communicable diseases – as well as on healthy ageing – is to develop systems (including health systems) that allow individuals to maintain their community and social networks [61]. The recent developments of social capital measurement in ego-centered networks [62] could potentially offer more sophisticated tools for identifying the structural specificities and content of interpersonal relations in respect to health conditions. Finally, given the current economic crisis, the enhancement of social networks could be an inexpensive yet highly effective solution, together with the increase of social support for the improvement of health and well-being of persons with neurological diseases, too. Community and network-centred approaches have been suggested to promote self-management, meaning a person taking control of her/his condition and social support for self-management can also contribute to lowering healthcare costs [63].

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5. Conclusion

The findings of the studies explored in this review indicated an increasing research focus upon social relationships of persons with MS. It appears that the ability to seek and maintain social relationships and participate in social and daily activities is important for persons with MS and has an impact on their quality of life as well as on the health functioning, whilst mobility and stigmatisation issues hinder their social functioning. Other relevant issues emerged, such as employment difficulties, concealing MS from others, and inadequate formal and informal received support. A series of psychological and emotional factors also emerged, with depression and anxiety caused by MS being the most prevalent. From the current scientific literature, it is clear that social relationships have an impact on the health and well-being of persons with MS, especially in terms of their psychological state, and vice versa, psychosocial factors have also been linked to pathogenesis. However, the various aspects of the impact of social capital components and social support have not been extensively studied in relation to MS. Therefore, studies that further explore the social relationships and social capital components of persons with MS and healthcare practices should adopt a more biopsychosocial approach to treatment, as this could prove highly beneficial for the health and general well-being of persons living with MS.

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Declaration of interest

The authors report no conflicts of interest.

Ethical approval

No ethical approval was required for the current study.

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Table 1. List of the selected studies (in chronological order); including information on sample size and measures/instruments for assessment of social capital components, social support and/or relevant concepts.

Study	Publication year	Sample size	Measures/instruments used for assessing social capital components, social support, and/or relevant concepts
[32]	2000	305 patients with MS and 223 relatives.	Population-based survey also on recreational activities and social interactions with friends and family members before and after the onset of MS and when a change was reported an attempt to identify the reasons for this was made.
[30]	2004	136 MS participants.	Domains of functioning assessed by the WHODAS II including: understanding and communicating; getting around; self-care; getting along with others; life activities; and participation in society.
[51]	2004	329 patients with MS, 315 cancer patients, and 391 non-random healthy participants.	Questionnaire including 30 items of loneliness experience.
[48]	2005	502 people with MS.	The 19-item Benefit Finding subscale (BFS) and respondents were also asked to describe their main MS-related problem experienced in the last month.
[43]	2005	Eight people with MS and six relatives.	Interviews conducted with people with MS in the middle and late stages of illness and their relatives, on how they had faced crucial life events such as family life, networks, career, and long-term knowledge of healthcare services.
[39]	2006	27 older adults with MS.	First interview using an in-depth semi-structured interview guide focused on daily routine, activities, roles, disease related information, changes experienced with age, the meaning of health, use of health-related services, and unmet service needs.
[46]	2006	19 persons with MS.	Interpersonal functioning was assessed at baseline using the Inventory of Interpersonal Problems-Circumplex, (IIP-C).
[42]	2006	Eight had MS and six were relatives.	Interview questions focused also on how people with MS and their relatives interpret symptoms, diagnosis and adjustment to disability and their reaction to societal attitudes towards sickness.
[45]	2007	Secondary analysis of data from 659 women with MS.	The Personal Resource Questionnaire (PRQ) Part 2 measured social support and the Social Relationships Subscale (items 49–58) of the Demands of Illness Inventory (DOII, modified version) assessed the social responses of illness.
[41]	2007	Eight community-dwelling adults with MS.	Semi-structured interviews in which participants were presented with descriptions of a variety of communication situations and rated their satisfaction with each situation and why they felt as they did.
[50]	2007	329 MS patients, 315 cancer patients, and 391 participants from the general population.	34-item questionnaire on coping strategies that participants had used and found beneficial.
[31]	2008	112 community-dwelling persons with MS.	28-item survey on common activities in which participants were expected to participate regarding four areas of participation: routines, recreation, responsibilities and relationships.
[49]	2009	41 participants with MS and 41 healthy control participants.	The Social Support Revaluate Scale (SSRS) was designed to assess individual emotional experience and satisfaction with being respected, supported and understood in society. The scale had 10 items, including three dimensions: objective support, subjective support and social support.
[35]	2009	Eight individuals diagnosed with MS.	Semi-structured focus group interview on the problems and feelings associated with MS and how these affect day-to-day life, their values and beliefs and how they see themselves.
[47]	2010	451 Veterans with MS.	Perceived social support measured using the Medical Outcomes Study Modified Social Support Scale (MSSS). The 18-item scale, a component of the Multiple Sclerosis Quality of Life Instrument, assesses four aspects of perceived social support: tangible, emotion/information, affection and positive social interaction.
[55]	2010	210 persons with MS and 108 healthy subjects.	Social support assessed using the Social Provisions Scale (SPS).
[57]	2010	Final intent-to-treat sample of 127 persons with MS.	Social support was assessed using the UCLA-Social Support Inventory. Authors focused on two aspects of social support: level of received support and satisfaction with that support.
[34]	2010	Nine participants with MS.	Semi-structured interviews including items on what MS fatigue is like, the kind of changes that are brought about by fatigue, how one is handling it, and how one discusses it with one's family and friends.
[33]	2010	48 women with a self-reported diagnosis of MS.	Participation was measured by the Role-Emotional, Role- Physical, and Social Functioning subscales of the SF-36.
[56]	2011	12 participants with physician-diagnosed MS.	Focus groups with open-ended questions on symptoms, challenges, overcoming challenges, and how people managed their symptoms.

[28]	2012	330 persons with MS completed the assessment of social functioning at baseline and 319 at 3 years.	Social functioning was assessed using the Environmental Status Scale (ESS). Quality of life was assessed using the Multiple Sclerosis Quality of Life (MSQoL)-54 questionnaire. Depressive symptoms were assessed using the Hamilton Depression Rating Scale (HDRS). Fatigue was measured using the Fatigue Impact Scale (FIS), which assesses the effects of fatigue in terms of physical, cognitive, and psychosocial functioning.
[37]	2013	1,372 individuals with MS.	Health promotion behavior was assessed using the Health-Promoting Lifestyle Profile II (HPLP II). The 52-item scale is composed of six subscales: health responsibility, physical activity, nutrition, spiritual growth, interpersonal relationships and stress management.
[44]	2013	415 women with physical disabilities, with 25% of them having MS.	Survey including variables on social resources using two measures: a) Social isolation: using 3 items from the Human Population Laboratory Study of Alameda County on the number of close friends and relatives participants have and how many of them they see at least once a month; and b) Social support: using an abbreviated version of the Medical Outcomes Study Social Support Scale, which consists of two items from each of the four subscales plus an additional item assessing overall satisfaction with social relationships.
[53]	2014	172 participants with MS.	World Bank's social capital integrated questionnaire (SC-IQ) and Multiple Sclerosis Quality of Life (MSQOL) -54.
[29]	2014	Eight participants with MS.	Focus groups were used to generate first-person narratives on psychosocial difficulties.
[40]	2016	Eight participants with MS.	Focus groups and the interviews were used a topic guide including open-ended questions to initiate discussion on psychosocial difficulties and factors associated with them.
[25]	2016	606 persons with MS.	Individual perceptions of the intrapersonal, interpersonal, and environmental factors that inhibit health-promoting behaviors were measured by the Barriers to Health-promoting Activities for Disabled Persons Scale. Health-promoting Behaviors were operationalized with the Health-promoting Lifestyle Profile II (HPLPII).
[36]	2016	15 participants with MS.	Interview on four topics: exploration of meaningful social relationships (types, natures, influences, changes), the influence of MS on these relationships, perceptions of the impact of MS on others' social relationships, and the influence that social relationships might have on how MS is perceived.
[54]	2017	150 adult patients with MS.	The Medical Outcomes Study Social Support Survey was used to assess the social support network. Healh-related quality of life was assessed using the Health Status Questionnaire (SF-36v2) Portuguese version of the Medical Outcome Study 36-Item Health Survey Short Form (SF-36).
[26]	2017	446 participants with MS.	Participants were asked to list the initials of all of their close friends who shared their diagnosis of MS. Participants were also asked to list the initials of all of their close friends who experienced physical disability. The Older People's Quality of Life Questionnaire-Brief (OPQOL) was used to measure quality of life. Satisfaction with social roles was measured using the standard four-item short form from the PROMIS item bank for satisfaction with social roles and activities.
[27]	2017	215 adults with MS older than 60.	Social support measured with the Personal Resource Questionnaire (PRQ). The frequency of health promotion activities was measured by the Health-Promoting Lifestyle Profile II (HPLP II). This measure includes 52 items organized into six subscales (i.e., physical activity, health responsibility, spiritual growth, interpersonal relations, nutrition, and stress management).
[52]	2017	508 individuals diagnosed with relapsing/remitting or secondary/progressive MS.	The social participation questionnaire consisted of four items on how frequently participants engaged in various social activities over the past 6 months, for spending time with friends in-person, friends online, community group in-person, and community groups online.
[38]	2017	319 individuals with MS.	The Social Support for Exercise Scale (SSES) consists of twelve questions to separately evaluate the role of both family (or members of the household) and friends in providing the participant with support for their exercise behaviour over the previous three months.
[58]	2018	250 Iranian women with MS.	The Health Promoting Lifestyle Profile-II (HPLPII)'s Persian version. The modified social support questionnaire included 18 items on four domains of social support: (a) tangible support, (b) emotional informational support, (c) affectionate support, and (d) positive social interaction.

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Table 2. The themes that emerged based on the main findings of selected studies.

- Impact of physical and cognitive impairments and physical and social environmental barriers on social functioning
- Stigma
- Psychosocial, emotional and mental challenges
- Association of quality of life with social capital components and social support
- Contribution of social support to improvement of social functioning and health.

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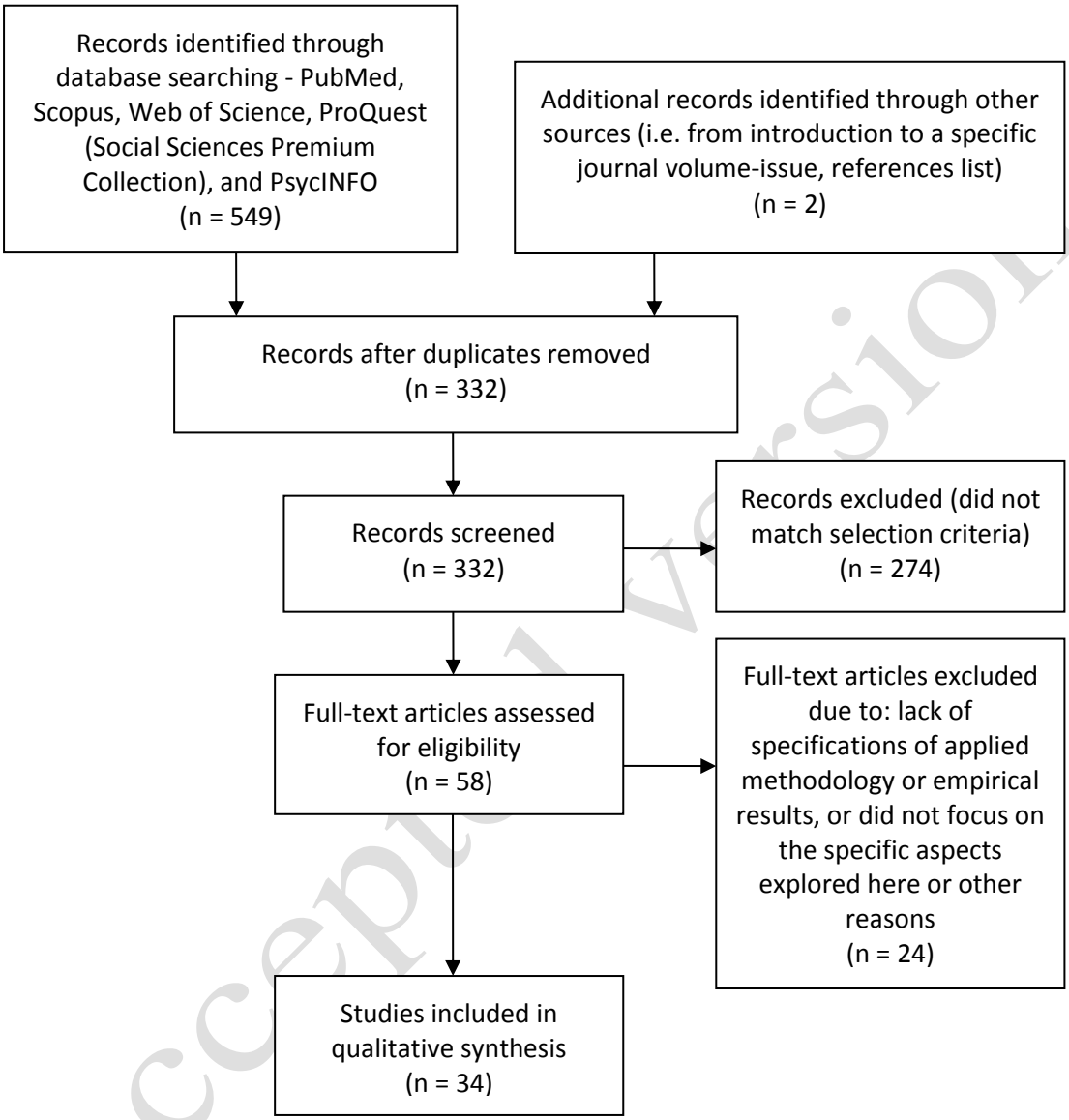
Figure 1. Process of inclusion of studies in the current systematic literature review (PRISMA Flow Diagram [21]).



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