Identifying Barriers to and Facilitators of Health Service Access Encountered by Individuals with Multiple Sclerosis

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CME/CNE Information

Activity Available Online: To access the article, post-test, and evaluation online, go to https://www.highmarksce.com/mscare.

Target Audience: The target audience for this activity is physicians, physician assistants, nursing professionals, mental health practitioners, rehabilitation therapists, and other health care providers involved in the management of patients with multiple sclerosis (MS).

Learning Objectives:

1) Identify several specific barriers and facilitators encountered by people with MS when attempting to access health care services, which the learner should consider in their clinical practice.

Accreditation Statement:

In support of improving patient care, this activity has been planned and implemented by the Consortium of Multiple Sclerosis Centers (CMSC) and Delaware Media Group. The CMSC is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

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Background: The symptoms of multiple sclerosis (MS) can be diverse, complex, and progressive, creating a need for frequent and long-standing health care services. The purpose of this scoping review was to identify the barriers people with MS encounter when attempting to access multidisciplinary health services and the reported facilitators for better access to health services.

Methods: The MEDLINE, Embase, and CINAHL databases were searched, without date or geographic restrictions, using the following terms: *multiple sclerosis, health services accessibility, health care access, health care delivery,* and *delivery of health care*. After screening based on exclusion criteria, 23 articles were included in the final review.

Results: Five main themes were identified as barriers and facilitators to accessing health services: 1) information (information available to people with MS, health care provider knowledge of and familiarity with MS), 2) interactions (interactions between health care providers and people with MS, social networks and support of people with MS, collaboration among health care providers), 3) beliefs and skills (personal values and beliefs, perceived time to travel to and attend appointments, and self-assessment of symptoms and needs of people with MS), 4) practical considerations (wait times, physical barriers, affordability of services), and 5) nature of MS (complexity and unpredictability of disease symptoms).

Conclusions: People with MS and their health care providers may benefit from structured and comprehensive MS-specific education to address barriers to accessing health care services. The education can ultimately facilitate the process of addressing unmet health care needs and contribute to a greater quality of life for people with MS. ***Int J MS Care*. 2021;23:37-44.**

Multiple sclerosis (MS) symptom presentation can be diverse, with an unpredictable disease course, creating a need for frequent and long-standing health care services from a variety of health care professionals, including physicians, physical and occupational therapists, and mental health professionals.[1-3] Despite frequent interactions with health care providers, people with MS continue to report unmet health care needs and dissatisfaction with aspects of their current level of care.[4-6] Among these reports are concerns regarding discontinuity of care, lack of information about diagnosis and symptom management, and lack of patient-centered care. Indeed, unmet health care needs can contribute to ongoing MS symptoms, resulting in physical, psychosocial, and occupational consequences for people with MS.[1]

To promote patient-centered care, target improved health service access, and, ultimately, improve quality of life (QOL), it is essential to identify the unique barriers contributing to health care service access for individuals with MS. It is also helpful to identify how existing aspects of care may facilitate access to health services. This knowledge is critical as research has demonstrated that removing barriers to MS physical and mental health care contributes to improved health-related QOL for people with MS.[7]

The objective of the present study was to conduct a scoping review of the current literature to identify both the specific barriers that individuals with MS encounter when attempting to access multidisciplinary health services and the reported facilitators of improved access to health services.

Methods

Guidelines outlined by Arksey and O'Malley[8] and subsequent recommendations by Levac and colleagues[9] guided the methods for this scoping review. In brief, the research question and search strategy were developed, relevant articles were identified and selected according to exclusion criteria, data were extracted and charted, and main themes were identified, as described herein.

Search Strategy

The search was guided by the research question, "What are the barriers to and facilitators of health service access for individuals with MS?" Three databases were searched: MEDLINE, Embase, and CINAHL. Search terms included *multiple sclerosis, health services accessibility, health care access, health care delivery,* and *delivery of health care.* Studies were considered up to July 23, 2018, the date the final database search was conducted.

Inclusion and Exlusion Criteria

A total of 857 citations were exported to a reference manager (EndNote; Clarivate), and 156 duplicates were removed.

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The remaining 701 abstracts were reviewed for inclusion (see the exclusion criteria below), and from these, 73 articles were downloaded for further full-text review (Figure S1, published in the online version of this article at ijmsc.org).

Articles were excluded if 1) no specific barriers to or facilitators of health service access were identified by the research, 2) participants involved combined neurologic groups wherein MS-specific results were not presented separately, 3) the participants spoke about a health behavior (eg, exercise) rather than about accessing a health service (eg, physiotherapy), 4) the text was written in a language other than English or French, and/or 5) no full-text article was available for review. There were no date or geographic restrictions for inclusion.

Data Extraction and Identification of Main Themes

Based on the study criteria, 23 articles were ultimately included in the present review. For each of these articles, characteristics of the study population (eg, number of participants, age, MS subtype) and study design (eg, qualitative vs quantitative) were tabulated, along with the specific barriers and facilitators reported by study participants. Next, the extracted information about barriers and facilitators was grouped by independent reviewers (C.D.M. and N.F.) to identify the main themes described later herein. A third reviewer (S.G.) was consulted to resolve discrepancies, when needed. When multiple barriers and/or facilitators were reported in a single study, the results were grouped into more than one theme.

Results

After final examination, seven quantitative, 13 qualitative, and three mixed qualitative and quantitative studies were included in this scoping review, for a total of 23 articles (Table 1). Studies were included in this review only if specific barriers and/or facilitators to accessing health care services were identified. These barriers and facilitators were categorized into five major themes: information, interactions, beliefs and skills, practical considerations, and the nature of MS (Figure S2). Findings in each theme were further grouped into several subthemes.

Information

The first theme, information, concerned the availability of MS-specific information to people with MS and health care provider knowledge of and familiarity with MS.

Information Available to People with MS

Lack of information regarding services available to people with MS was cited by nine distinct studies as a significant barrier to accessing health care services.[4,10-17] Services cited in these studies had a wide range and varied from MS-specific dental services[10] to care for lower urinary tract symptoms[13] and rehabilitation.[15] Three studies found that lack of information about physical aids, adaptations, and insurance/welfare benefits posed a barrier to accessing care.[4,12,17] In addition, understanding how the health care system operates, knowing how to navigate it, and knowing how to fill out necessary paperwork were identified as facilitators.[14]

Health Care Provider Knowledge of and Familiarity with MS

Seven studies highlighted that health care provider knowledge of MS-specific information influences how people with MS access health care services.[5,6,16,18-21] For instance, one study found that some people with MS had difficulties finding family doctors and neurologists who they perceived to be competent and knowledgeable about novel therapies.[5] Finding a mental health care provider who is a "good fit" and is knowledgeable about MS is another barrier that people with MS face.[21] Many study participants found educating their mental health care provider about MS exhausting and frustrating, causing one participant to stop seeking further treatment altogether.[21] General practitioners and nurses both highlighted a lack of training and education with respect to new treatment options and mental health needs of people with MS, respectively, as barriers to providing care.[6,20]

One study found that increasing awareness of available services for both people with MS and health care providers was helpful in decision making concerning candidacy for available services.[6] Nurse liaisons were noted in one study as important in this regard.[16] That is, nurse liaisons improved knowledge of MS for both people with MS and affiliated health care professionals; in addition, they recognized overlooked symptoms and improved health care access for people with MS by increasing referrals to needed services.[16] Liaison nurses, as well as specialist nurses and clinical nurse practitioners, may perform many tasks that are key to a patient's health management plan. They give information and advice to patients and their families and coordinate different aspects of the health care plan.[16]

Interactions

The second theme, interactions, encompassed the interpersonal relationships and communication that affect access to health care services for people with MS. Three subthemes were identified: 1) interactions between health care providers and people with MS, 2) collaboration among health care professionals, and 3) social networks and support.

Interactions Between Health Care Providers and People with MS

Nine distinct studies identified barriers and facilitators that lend to this subtheme.[6,11,16,17,21-25] The importance of interactions between health care providers and people with MS was highlighted by two studies. For example, negative interactions with health care professionals (described as "highly emotive") affected how people with MS accessed health care services for years.[6] People with MS also noted that ineffective listening and communication by their health care providers contributed to "unhelpful care."[25]

Table 1. Summary of selected articles regarding barriers to and facilitators of health service access in MS

Authors, year	Country	Main study objective	Methods	Sample	Size, No.
Baird et al,[10] 2007	UK	Determine impact of MS on oral health care maintenance and patient attendance at dental practices	Quantitative	PwMS	289
Becker and Stuifbergen,[11] 2004	USA	Determine barriers to health promotion experienced by PwMS	Mixed	PwMS	557
Borreani et al,[12] 2014	Italy	Identify unmet needs of PwMS and investigate areas of intervention to meet unmet needs	Qualitative	PwMS Caregivers MS HCPs	22 30 18
Brucker et al,[13] 2017	USA	Identify barriers experienced by PwMS needing evaluation for urinary symptoms	Quantitative	PwMS	100
Campbell et al,[30] 2017	UK	Assess access and identify barriers to physiotherapy for PwMS	Quantitative	PwMS	1298
Dennison et al,[22] 2016	UK	Study perspectives from PwMS on nature of received and desired prognosis communication, and uncertainty of prognosis	Qualitative	PwMS	15
Edmonds et al,[4] 2007	UK	Assess perceptions of PwMS regarding their illness and care they receive	Qualitative	PwMS Caregivers	23 9
Finlayson et al,[14] 2004	USA	Examine unmet health care service needs from perspectives of PwMS, caregivers, and HCPs	Mixed	PwMS Caregivers HCPs	34 11 9
Galushko et al,[5] 2014	Germany	Assess unmet needs of PwMS who feel severely affected by MS	Qualitative	PwMS	15
Ghafari et al,[23] 2015	Iran	Study experiences of PwMS in adapting to MS	Qualitative	PwMS	25
Golla et al,[28] 2012	Germany	Assess perceived unmet needs of PwMS from the perspective of HCPs	Qualitative	HCPs	23
Helland et al,[15] 2015	Norway	Identify facilitators of and barriers to rehabilitation services for PwMS	Qualitative	PwMS	27
Hepworth et al,[18] 2003	UK	Study information needs of PwMS	Mixed	PwMS	2030
Johnson,[19] 2003	UK	Evaluate role of MS-specialized nurses in health care experiences, particularly diagnosis, of PwMS	Qualitative	PwMS	24
Kirker et al,[16] 1995	UK	Evaluate benefits of a liaison nurse for PwMS and HCPs	Quantitative	PwMS Cargivers	67 51
Mattarozzi et al,[24] 2017	Italy	Identify which care organization and service characteristics contribute to satisfaction of PwMS with their health care	Quantitative	PwMS	707
Methley et al,[6] 2017	UK	Explore perspectives and experiences of PwMS and HCPs of MS-related health care services	Qualitative	PwMS Caregivers	24 34
Methley et al,[20] 2017	UK	Explore perspectives and experiences of PwMS and HCPs of mental health services in PwMS	Qualitative	PwMS Caregivers	24 34
Ploughman et al,[25] 2012	Canada	Study experience of aging with MS of older PwMS	Qualitative	PwMS	18
Rintell et al,[21] 2012	USA	Explore experiences of PwMS receiving mental health care services	Qualitative	PwMS	54
Sutton et al,[29] 2007	USA	Determine how PwMS who received care from comprehensive care center report access to care, satisfaction, and perceptions of quality of care	Quantitative	PwMS	1403
Todd and Stuifbergen,[17] 2011	USA	Explore facilitators of and barriers to breast cancer screening for women with MS	Qualitative	PwMS	36
Wilkinson et al,[31] 2018	UK	Explore how MS HCPs believe their services adhere to NICE quality statements	Quantitative	MS HCPs	57

Abbreviations: HCP, health care provider; MS, multiple sclerosis; NICE, National Institute for Health and Care Excellence; PwMS, people with MS.

Poor communication and rapport with health care providers during diagnosis that results from a lack of understanding or empathy affected health service access.[17,22,23] A distressing diagnostic experience negatively affected future interactions with health professionals[22] and how people with MS follow prescribed treatments, both of which pose a significant barrier to accessing health care services.[23] Feeling rushed during consultations with health care providers and feeling that providers did not have time for them contributed to poor communication and was a barrier to health care access.[16,25] Research shows that having a nurse with whom to discuss sensitive topics and practical issues facilitated access to various services.[16,22]

Collaboration Among Health Care Professionals

Although open and effective communication between members of an interprofessional health care team is important for continuity of care,[26,27] lack of communication and coordination between health care professionals is a barrier to health service access.[4,6,28] Lack of continuity of care causes frustration for people with MS and even leads to certain health concerns not being addressed by health care providers despite repeated attempts by people with MS reiterating the concern.[4] Similarly, inadequate communication causing poor continuity of care can lead to loss of information and treatment plans being abandoned.[28] Seeking care at a comprehensive care center or an MS clinical center, where various services and health care providers are integrated, facilitated access to health care services.[21,29] For instance, people with MS found it easier to access mental health services via these clinics.[21]

Social Networks and Support

Three studies found that social isolation and lack of support from family and friends was a barrier to accessing health care services for people with MS.[11,14,30] Similarly, having supportive family members and friends nearby to help maintain health care routines, such as attending doctor appointments, was found to be a facilitator to health care access.[14,28] These data illustrate the importance of a strong social network to ensure continuous access to health care services.

Beliefs and Skills

The third theme, beliefs and skills, involved the perceptions of individuals with MS. Three subthemes were identified: 1) personal beliefs, 2) perceived time, and 3) self-assessment skills.

Personal Beliefs

Lack of confidence in one's abilities or appearance, and feeling embarrassed, was found to be a barrier to accessing health care services for people with MS in two studies.[11,17] Fears of being confronted with the realities of MS symptom progression and of being labeled as a patient with MS were also barriers to seeking health services such as rehabilitation.[15] In addition, believing that a particular health intervention would not have a positive effect was cited as a barrier.[11] Correspondingly, a positive attitude and being accepting of one's physical limitations contributed to greater health service utilization by individuals with MS.[14] These findings demonstrate the importance of addressing the beliefs and concerns of individuals with MS to overcome these barriers.

Perceived Time

This subtheme relates to the mindset of people with MS. Four studies found that believing that people with MS do not have sufficient time, or already have too many responsibilities and commitments, posed a barrier to people with MS to access health care services.[11,13,15,17] For instance, one of the main barriers to seeking urologic care was feeling that "they had enough problems to deal with," as voiced by 18.6% of people with MS included in one study.[13] Another study found that many people with MS did not use services at rehabilitation facilities for which they were eligible due to time restrictions and existing commitments.[15] The need for personalized, feasible care plans for people with MS to improve access to care was highlighted by the literature.

Self-assessment Skills

Self-assessment is considered the ability to assess changes and medical needs to seek out appropriate health care services. Four studies found that an inability to identify needs or a misidentification of symptoms by people with MS posed a barrier to accessing health care services.[6,12,14,20] For instance, determining the cause of low mood and whether it required mental health care intervention was difficult for people with MS.[20] These findings suggest that giving people with MS tools to self-assess may improve access to required health care services.

Practical Considerations

The fourth theme, practical considerations, included systemic-level and functional factors that individuals with MS encounter when seeking health services. Three subthemes were identified among these practical considerations, including concerns regarding 1) wait times, 2) physical barriers, and 3) finances.

Wait Times

Six studies noted that long wait times, primarily to access secondary care, and a paucity of specialized therapy centers was a significant barrier to accessing health care services.[6,20,21,23,25,31] People with MS noted particularly long wait times for appointments with specialists such as mental health professionals.[21,25] Similarly, people with MS who participated in another study noted delays in accessing community and secondary services.[6] These

findings highlight a need to address wait times and availability shortages for those with MS.

Physical Barriers

Physical barriers could hinder the ability of people with MS to access health services, including lengthy commutes and/or lack of accessible transportation options, inaccessible buildings, and lack of reserved accessible parking.[10,11,13,14,17,21,30] For instance, people with MS noted that stairs, heavy doors, and small changing rooms posed barriers to accessing dental services,[10] mental health services,[21] and breast cancer screenings.[17] These barriers can, therefore, affect access to health care services that are not directly linked to MS but contribute to the overall health of people with MS.

Finances

Three studies highlighted that affordability of services was a barrier to accessing health services.[11,13,21] For example, individuals with MS expressed concern about how to afford mental health services should they lose insurance benefits.[21]

Nature of MS

The fifth theme, the nature of MS, encompassed factors associated with MS symptoms and their complex interactions. Three studies noted that symptoms such as fatigue, pain, limited mobility, and cognitive impairment were barriers to accessing health care services.[11,17,30] For example, women with MS reported being unable to tolerate standing during procedures such as mammograms.[17] In addition, one study found that individuals with MS were not considered candidates for mental health service referral if their symptoms were not seen as separate mental health conditions distinct from MS.[20] Thus, the complexity of MS symptoms was seen as a barrier to accessing mental health services.

Discussion

In the present study, five main themes were identified as barriers and facilitators to accessing health services for people with MS: information, interactions, beliefs and skills, practical considerations, and the nature of MS. The present findings are similar to the barriers to and facilitators of health service access reported by other patient populations with chronic conditions. For example, during cancer consultations, individuals with cancer have reported that health care providers do not provide them with sufficient information, lack empathy in their communications, and perceive that there is no time to express concerns.[32] Similarly, differences in perspectives among patients and providers, insufficient time, and stroke-related impairments (eg, fatigue, cognitive impairment, dysregulated mood) are reported barriers to stroke rehabilitation, and frequent active communication and education, adequate resources, and effective and encouraging providers were facilitators.[33] Similar findings were also reported for people with epilepsy; social support, knowledgeable health care providers, and adequate medical insurance were key during the diagnostic process.[34] In addition, psychological barriers (eg, mental illness, frustration), cognitive impairments, mistrust of health care providers, and poor communication from health care providers posed barriers to health care self-management for these individuals.[35]

Overall, identifying the major barriers and facilitators experienced by people with MS is a critical first step in facilitating the changes needed to improve access to health services for people with MS. In the present study, a critical barrier to accessing health services concerned a lack of MS-specific information, for both people with MS and health care providers. Because individuals with MS reported being unaware of various services and supports available to them,[17,19] and perceived that their health care providers lacked MS-specific training,[5] both individuals with MS and their health care providers may benefit from structured, comprehensive MS-specific education. Research has shown that increased knowledge is necessary for disease self-management for people with MS, allowing them to be active partners in managing their chronic condition.[36,37] Furthermore, studies have also highlighted the benefit of having a dedicated health care professional (eg, a nurse liaison) to help individuals with MS navigate the health care system and identify possible sources of funding, including insurance.[16] In addition to consulting with health care providers, individuals with MS may wish to seek out publicly available educational resources through MS societies (eg, MS Society of Canada, National MS Society) and/or seek the assistance of an "MS navigator," an individual trained to provide MS-specific information. Health care providers may also wish to seek out professional development opportunities (eg, MS continuing education courses), such as those available through the Consortium of Multiple Sclerosis Centers (CMSC).

Another relevant barrier to accessing health services concerned the interpersonal interactions between individuals with MS and their health care providers. Some individuals with MS perceived interactions as nonempathetic, which disrupted the trust in the patient-physician relationship, leading the individual with MS to not follow their health care provider's recommendations.[23] Others felt too embarrassed to ask questions about specific concerns such as incontinence or sexual problems.[16] One major solution to this ineffective interaction is targeted communication interventions. There is strong evidence that such interventions enhance communication between patients and health care providers, allowing patients to obtain greater information and have a more active role in discussions.[38] Therefore, individuals with MS may benefit from specialized education about

how to ask specific, relevant questions and how to better communicate their perceived needs with their health care provider. At the same time, health care providers may benefit from specific training on effective communication with their patients, including the benefits of empathetic and patient-centered practices.[39,40]

Several studies found that the mindset of people with MS can positively or negatively affect access to health services. An important factor identified is one's outlook and attitude on the health service in question, and how they believe it will affect their QOL. This has been reported previously as a relevant factor affecting health care access and compliance for those with other chronic conditions, such as heart failure[41] and postoperative pain management.[42] One way to facilitate access to health care services for these individuals may be to provide more comprehensive patient-specific education by thoroughly discussing treatment plans and addressing any misconceptions that may exist.

The ability of a person with MS to self-assess and correctly identify their own needs affects access to health care services. It is, therefore, important to improve education by providing patients with MS with the tools they require to accurately identify and adequately communicate their needs to health care professionals. In addition, the complexity of the symptoms experienced by people with MS could pose barriers to health care access.[11,17,30] Multiple sclerosis is a heterogenous disease, with different subtypes and phases, as well as a wide array of potential symptoms.[43] These symptoms, including mobility issues and fatigue, greatly contribute to how people with MS access their health care services. Learning to communicate these barriers with health care professionals so that they can be addressed may improve access to health care services and enhance QOL.

Several practical matters were found to significantly affect access to health care services for people with MS. Financial and insurance-related considerations is one such factor. People with MS in several studies cited financial limitations and uncertainty of insurance coverage as a barrier to accessing health care services.[11,13,21] The economic burden is great for people with MS and their loved ones owing to the effect on employment for people with MS and others in the household, as well as the cost of medications, medical services, home modifications, and items such as mobility aids.[44,45] It would, therefore, be helpful to have information available for people with MS to clarify insurance options, rebates, and any other helpful resources available to alleviate financial concerns. One study has shown that assistance from a dedicated health care professional, such as a nurse liaison, can be helpful in identifying sources of financial assistance.[16]

Regarding limitations, this review used a language restriction (only articles in English and French were included). Further research on health care access should include health care providers and people with MS, as well as their informal caregivers, to get a comprehensive understanding of their diverse perspectives. In addition, it is necessary to optimize knowledge translation to people with MS, their loved ones, and health care providers to facilitate effective communication between these parties and ultimately improve QOL for individuals with MS. Knowledge can be drawn from studies in the context of other chronic conditions, such as cancer and type 2 diabetes.[46-49]

In conclusion, this scoping review of the current barriers and facilitators encountered by people with MS identified themes concerning information, interactions, beliefs and skills, practical considerations, and the nature of MS, all of which can inform potential changes in clinical practice and policy and guide future research. The results highlight that both individuals with MS and their health care providers may benefit from structured and comprehensive MS-specific education. The education can facilitate the process of addressing unmet health care needs and, ultimately, contribute to a greater QOL for people with MS. □

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PRACTICE POINTS

- When attempting to access health services, people with MS encounter barriers related to 1) lack of information, 2) varied interactions with health care providers and social support, 3) variable beliefs and skills (eg, personal values, time constraints), 4) practical considerations (eg, physical barriers, affordability), and 5) the complex nature of MS symptoms.
- People with MS and their health care providers may benefit from structured and comprehensive MS-specific education. The education can facilitate the process of addressing unmet health care needs and, ultimately, contribute to a greater quality of life for people with MS.

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