

Healthcare and Rehabilitation Needs of Individuals with Multiple Sclerosis

Benson Kinyanjui
Collin College

Bradley McDaniels
Virginia Commonwealth University

Michael Frain
Florida Atlantic University – Boca Raton

Malachy Bishop
University of Wisconsin – Madison

Chung – Yi Chiu
University of Illinois at Urbana –
Champaign

Beatrice Lee
University of Wisconsin – Madison

Lebogang Tiro
Pennsylvania State University

Abstract

There is little research delineating the healthcare and rehabilitation needs of individuals with multiple sclerosis (MS) that is based on the perspectives of those individuals themselves. The medical community is largely well-informed about disease progression, symptoms, and treatment of MS, but little is known regarding the barriers and unmet needs that individuals with MS experience in their interaction with healthcare and rehabilitation systems and providers, and in their efforts to maintain healthy, productive, and participatory lives. In this article, we provide a comprehensive summary of the most frequently identified healthcare and rehabilitation needs of individuals with MS based on a review of over 500 articles, from which 29 articles were selected for inclusion as they specifically addressed the needs or unmet healthcare and rehabilitation needs of people with MS. Based on our review, we identified 11 categories of needs, which we discuss in the context of three broad categories, including (a) emotional and psychological support, (b) healthcare and rehabilitation, and (c) transportation, home care, and financial needs.

Keywords: multiple sclerosis, health care, priorities, needs, expectations

Multiple sclerosis (MS) is a chronic disease of the central nervous system that affects approximately 2.5 million people worldwide, and recently-revised US prevalence estimates, based on research funded by the National Multiple Sclerosis Society, suggest that almost one million Americans are living with MS (Asche, Singer, Jhaveri, Chung, & Miller, 2010; National Multiple Sclerosis Society [NMSS], 2018; Sawcer, Franklin, & Ban, 2014; Zwibel & Smrka, 2011). Despite its prevalence, however, the number of studies exploring the healthcare and rehabilitation needs of those with MS is limited. This is particularly problematic because people with MS (PwMS) are widely reported to have more unmet needs in comparison to those with other disabilities (Patten et al., 2012).

MS is an immune-mediated condition characterized by intermittent and recurrent episodes of inflammation that result in damage to the myelin that surrounds central nervous system neuron axons, and to the underlying axons themselves (Bishop & Rumrill, 2015). Depending on the size and location of the resulting lesions, MS may result in a wide range of symptoms and may affect physical, sensory, cognitive, and emotional functioning (DeLuca & Nocentini, 2011). Commonly experienced symptoms include fatigue, pain, numbness and tingling, mobility limitations, cognitive impairments, affective disorders, visual impairments, bowel and bladder dysfunction, and sexual dysfunction (Antao et al., 2013). The course of MS is frequently characterized by alternating episodes of neurological symptoms and remissions and, as there is no cure for MS, PwMS generally experience high levels of interaction with healthcare and rehabilitation throughout their lives.

Due to the nature of the MS disease process, the experience of living with MS is unique to each individual, in terms of both

the symptoms experienced and the broader psychosocial impact. The psychosocial impact of MS can be influenced by a range of variables, including age at diagnosis, demographic variables, functional status, healthcare and rehabilitation access, and various social and socio-economic factors (Kersten et al., 2000; Minden, Frankel, Hadden, & Hoaglin, 2007). Because MS is typically diagnosed in early to mid-adulthood, psychosocial disruption frequently includes a premature exit from the workforce and changes in established social and family roles.

MS consumers are frequently excluded from the design and delivery of MS care, and as a result, our current understanding of the healthcare needs, priorities, and preferences of PwMS is limited (Forbes, While, & Taylor, 2007). Furthermore, needs assessments and health care satisfaction surveys that have been conducted among PwMS have frequently been characterized by limitations in terms of informing healthcare and rehabilitation services. These limitations include that this research is generally based on relatively small and localized samples, and these studies are frequently based on standards developed by researchers and health care professionals, and are thus limited in their capacity to identify the consumer's perspective (Defriez, Griffiths, Millett, Thakrar, & Winterbotham, 2003; Forbes et al., 2007; Freeman & Thompson, 2000; Gottberg et al., 2008; Heesen et al., 2007; Hepworth & Harrison, 2004; Iezzoni, Davis, Soukup, & O'Day, 2002; Koopman, 2003). For the most part, the existing assessments of MS patients' healthcare experiences have documented "a general dissatisfaction" (Forbes et al., 2007). This dissatisfaction is related to many factors that are amenable to improvement through increased attention to the consumers' perspective, such as the management and effective communication

of the diagnosis; inconsistent provider availability; limited accessibility of care facilities; the lack of availability and accessibility of specialized services; the lack, or poor quality, of information from providers; inadequate provider communication skills; and poor coordination of care (Defriez et al., 2003; Freeman & Thompson, 2000; Gottberg et al., 2008; Greenfield, Kaplan, & Ware, 1985; Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Hakim et al., 2000; Heesen et al., 2007; Hepworth & Harrison, 2004; Iezzoni et al., 2002; Kaplan et al., 1995; Koopman, 2003; Lerman et al., 1990).

Comprehensive and effective MS healthcare and rehabilitation, in which consumers are both well-informed and active participants, necessitates a thorough understanding of those elements that are important to the participants. The purpose of this article is to provide a comprehensive review of the existing research literature on the health and rehabilitation needs of persons living with MS in order to promote effective rehabilitation and health information and service delivery. To achieve this purpose, we completed a thorough review of the existing literature relevant to the healthcare and rehabilitation needs of PwMS. This review was completed as part of a broader National Multiple Sclerosis Society (NMSS)-funded project to identify the health care priorities of Americans living with MS.

Method

An electronic search of various databases including PubMed, CINAHL, Medline and EBSCOhost databases was conducted using several keywords including 'multiple sclerosis,' 'health,' 'healthcare,' 'rehabilitation,' 'needs,' 'unmet needs,' and 'needs assessment.' The search focused on peer reviewed journal articles published between 1995 and 2015. In addition, a manual search was conducted using

reference lists from obtained articles. Altogether, the search yielded 513 articles excluding duplicates. Articles that did not specifically address needs or unmet needs relating to PwMS, general commentaries, and anecdotal accounts were excluded from the review. Out of the 513 original articles, 29 met selection criteria for this review.

The selected articles included participants from a variety of geographic regions. Nineteen of the needs assessments were conducted in Europe (France, Germany, Ireland, Italy, Netherlands, Spain, Sweden, Switzerland, United Kingdom); five were conducted in North America (Canada, USA); three were conducted in Australia; one in South America (Argentina); and one in the Middle East (Iran). Sample sizes in the studies ranged from 13 to 2,805 with response rates of between 25% and 80%. Many of the studies did not indicate the gender or ages of the participants, but for those that did, ages ranged from 19 to 92 years. With the exception of one study, which focused on people with primary progressive MS (PPMS), all studies were inclusive of MS courses. Nineteen articles addressed the needs of PwMS exclusively; four focused on the needs of PwMS and those of caregivers; and two addressed the needs of PwMS, caregivers, and healthcare professionals. One study focused on the needs of PwMS as perceived by healthcare professionals, and one related to the unmet needs of healthcare professionals themselves.

Following a thorough review of the selected articles, we identified 11 categories of unmet needs, which we frame in terms of three broad healthcare and rehabilitation topics, including (a) emotional and psychological support, (b) healthcare and rehabilitation, and (c) transportation, home care, and financial needs. Within the emotional and psychological support category we included needs related to

psychological support, social support, and self-actualization. In the healthcare and rehabilitation needs category we included needs related to coordination of care, equipment, and information needs. The third category included needs related to transportation, home care, and financial needs.

Emotional and Psychological Support Needs

In the area of emotional and psychological support PwMS have identified a range of needs. These include emotional support, the need for which varies over the course of living with MS and which is associated with the need for counseling, psychological support, social support, and needs related to self-actualization.

Emotional Support

From the moment a diagnosis is provided, emotional support is critical for individuals with MS. Medical professionals need to be aware of the emotional impact that an MS diagnosis brings and encourage the necessary social support (Defriez et al., 2003; Holland et al., 2011). Individuals with MS report wanting counseling services to be available immediately following diagnosis and when unexpected changes occur with disease progression. Counseling may serve to ensure that PwMS are adequately emotionally and psychologically prepared and supported (Holland et al., 2011; Ponzio et al., 2015). Because many PwMS may have never needed counseling prior to their diagnosis, the terms awareness and education may be more acceptable than counseling to some individuals (Holland et al., 2011). Regardless of the term used, psychological or social support was identified as an unmet need by nearly three quarters of individuals recently diagnosed with MS (Ponzio et al., 2015).

The greatest need for emotional support is during times of unanticipated changes or symptom exacerbation and following initial diagnosis. Not only do PwMS desire and need emotional support from others, they also frequently require support with activities of daily living such as housework, shopping and cooking (Patten et al., 2012). As a result of the challenges associated with MS, PwMS frequently have multiple caregivers (Patten et al.). Frequently, the caregiver is a spouse or parent who may themselves benefit from the receipt of MS education, specialized training, and psychological support in order to effectively assist and care for their loved one (Edmonds, Vivat, Burman, Silber, & Higginson, 2007). MS typically occurs more frequently in females, and, because the male caregiver may be unfamiliar with caretaking roles and duties, they may particularly be in need of guidance and support (Lee, Dedios, Simonette, & Lee, 2013). Literature clearly establishes the emotional, psychological, and physical toll on caregivers of individuals with disabilities, and affective interventions and respite services have been identified as important supports (Holland et al., 2011).

Psychological Support

Psychological support needs are common among individuals with chronic illness and disability, and in twelve of the MS needs assessments reviewed psychological support was identified as an unmet need. Needs specifically identified in this category included counseling; dealing with anxiety, depression, psychological stress, grief, anger, sadness, mood issues; and mental health.

Benbow and Koopman (2003) conducted a clinic-based assessment of the psychological needs of 353 people with MS and 240 significant others. Using a quantitative questionnaire developed

through focus groups, the participants identified unmet needs categorized in the broad domains of general psychological needs, psychological needs related to specific resources, and psychological needs related to interaction with the medical community. Across all participants, psychological needs were ranked as important or very important more frequently than needs in any other category in the survey. In the general needs category, PwMS indicated a need for support from others, a need to feel productive, and the need to maintain control as the most important needs. Resource-specific psychological needs included education for children regarding MS and its symptoms and progression and family therapy. Regarding interaction with healthcare professionals, PwMS perceived that the greatest need was for their physicians to demonstrate interest in their condition and to be supportive and positive, especially in telephone conversations. Ultimately, the study identified the most important psychological needs of PwMS as being the availability of positive social support, assistance with feeling productive, maintaining a feeling of control, supportive and interested providers, and positive telephone responses from providers.

Brandon (2007) reported that mental health issues, particularly those associated with the loss of control and uncertainty about the future, are not adequately addressed for PwMS. Borreani et al. (2014) reported that although most participants did not independently list uncertainty about the future as an unmet need, issues around death or end of life emerged as being largely unaddressed. Additionally, issues pertaining to advance care directives emerged as important counseling topics for people with severe MS and their caregivers. Borreani and colleagues also identified unmet needs in the areas of intimacy and sexuality, and

psychological support in adjusting to functional changes associated with MS.

Lorefice et al. (2013), using a questionnaire to assess the need for psychological support at diagnosis determined that the majority of PwMS (70%) and their caregivers (85%) both reported a need for psychological support at the time of diagnosis. When assessing post-diagnosis needs, PwMS considered psychological support less necessary (19%), while almost half of caregivers (49%) maintained the need for psychological support. These findings were similar to those of Gottberg et al. (2008) and Abolhassani, Yazdannik, Teleghani, and Zamani (2015), who reported in their studies that PwMS who experienced psychological problems expected to receive consultation services but many did not. In addition, Egger, Muller, Bigler, and Spirig (2012) noted that 30% of family members reported the need for psychological support to help them manage the challenge of dealing with their loved one's illness. In an Australian study, McCabe, Ebacioni, Simmons, McDonald, and Melton (2015) examined psychological, educational, and peer support needs of PwMS in light of age, gender, and disease severity. Remarkably, the study had 2,805 participants, an 80% response rate, and covered a wide range of ages (19 to 92 years of age). The participants, irrespective of age, gender, or disease severity, indicated that they had limited access to relationship and family counseling services and also indicated low satisfaction with the amount of psychological assistance they received when first diagnosed with MS.

Social Support

The majority of individuals with MS indicate that they have unmet social needs (Ponzio, Tacchino, Zaratini, Vaccaro, & Battaglia, 2015). Social support has long

been considered to positively correlate with health outcomes (Antonucci, Ajrouch, & Birditt, 2013). Social support was identified as a need in a number of the reviewed studies. This category encompasses support from family members, neighbors, coworkers, and others that PwMS might interact socially with in church, school, or support groups. Koopman, Benbow, and Vandervoort (2006) used the results of a previous needs assessment (i.e., Benbow & Koopman, 2003) to identify the 10 most important needs of PwMS and their significant others and found that social support was ranked most important by most of the participants. Galushko et al. (2014), found that people severely affected by MS ranked the support of family and friends as the most important unmet need. Participants in that study overwhelmingly reported decreasing social networks as problematic, and some reported having experienced a breakdown of a relationship as a direct result of MS. Strupp et al. (2012) found that the lack of social integration was strongly correlated with perceived negative effects of MS.

Golla et al. (2011) investigated the needs of people with severe MS, as perceived by their healthcare professionals, and nurses and social workers reported support from family and friends (in managing everyday life and accompanying them to medical appointments) and maintaining biographical continuity (retaining position and role in family and society) as the most important unmet needs for people with MS.

Lorefice et al. (2013) reported that for PwMS, diminishing relationships at work can dramatically affect social support networks. As individuals with MS search to connect with others, support groups can serve as a vehicle for positive social interactions. Unfortunately, Finlayson, Van Denend, and Hudson (2004) indicated that

PwMS frequently encounter barriers to successfully accessing support groups.

Self-Actualization

Unmet needs related to self-actualization were identified in five of the studies in this review. Unmet needs pertaining to participation in employment, education, social and recreational activities, hobbies, and religious activities were included in this category. Brandon (2007) reported that participants with MS indicated that they wanted to participate meaningfully in their community, but were occasionally hindered by inability to access facilities such as swimming pools. Employment was associated with both independence and a perceived better quality of life. In fact, Wollin, Yates, and Kristjanson (2006) reported the loss of employment and loss of independence was devastating to respondents. Eighty-seven percent of the participants in Koopman et al. (2006) reported a need to feel productive through meaningful employment. Kersten et al. (2000) and Oeseburg et al. (2004) were among others who found the need for self-actualization expressed by PwMS.

Employment is one of the main sources of social interaction and involvement, fulfilling one's need for social participation and support, in addition to being a critical component of subjective well-being and quality of life (Chiu, Chan, Bishop, da Silva Cordoso, & O'Neill, 2013). Diagnosis with MS too frequently results in a premature exit from the workforce (Holland, Schneider, Rapp, & Kalb, 2011; Ponzio et al., 2015). In fact, the literature suggests that although nearly two-thirds of individuals with MS are employed at the time of diagnosis (Rumrill, Hennessey, & Nissen, 2008), a significantly smaller percentage (20%) remains employed 10 years post-diagnosis (McFadden et al., 2012). Further, among PwMS who are unemployed, nearly 75% report that they are

interested in re-entering the workforce (Rumrill, 2006). Further attention to the vocational needs of PwMS as a critical component of self-actualization is clearly necessary, including more effective dissemination of information and delivery of services that allow people to make informed decisions about employment, and to remain as independent as possible (Ponzio et al., 2015).

Healthcare and Rehabilitation Needs

Fifteen of the needs assessments in this review mentioned healthcare services among the perceived unmet needs of PwMS. These services included medical treatment, physical therapy (PT), occupational therapy (OT), speech and language therapy (SLT), and rehabilitation. Based on feedback from focus groups, Holland et al. (2011) reported that a majority of PwMS perceived inadequacies in the provision of medical treatment regarding symptom management and rehabilitation. In particular, although PT and OT were reported to be desired and beneficial services, a lack of insurance coverage precluded many of the participants from obtaining these therapies. Forbes et al. (2007) surveyed 445 PwMS and from the seven major categories that emerged from the responses, the need for comprehensive medical services was the most prevalent, with 29% of the respondents indicating a desire for “effective disease modifying therapies as their single greatest need” (p. 18). Similar results were noted in the work of Kersten et al. (2000) and Oeseburg et al. (2004).

Coordination of Care

Universally, medical professionals, families, and PwMS cite inadequate coordination of care and having access to all

needed services as major obstacles (Golla et al., 2011; Holland et al., 2011). PwMS need a team of accessible and coordinated medical professionals who can effectively communicate with one another to facilitate necessary services and ensure continuity of care. Properly coordinated multi-disciplinary care (e.g., OT, PT, neurologist, psychologist) is critical for addressing the variety of treatment challenges faced by PwMS (Holland, et al., 2011). Among the reviewed studies, both a strong need for and a dissatisfaction with effective coordination of care were noted (Borreani et al., 2014; Senders, Sando, Webeh, Peterson-Hiller, & Shinto, 2014).

Equipment Needs

The need for equipment or assistive devices was mentioned in four of the studies included in this analysis. Some studies did not elaborate on the types of equipment, but where specified, those needs included wheelchairs, hoists, and shower aids. In a 2-year prospective study of 219 outpatients with MS, Ytterberg, Johansson, Gottberg, Holmqvist, and von Koch (2008) reported that the need for assistive devices emerged as the second most important unmet need among PwMS, with 69% of respondents identifying that need, and only 31% perceiving that it was adequately met. Further, Kersten et al. (2000), in their survey of PwMS in five European countries, found that 14% listed equipment as an unmet need, a finding that was similar to that of Oeseburg et al. (2004). Moreover, Brandon (2007) found that equipment was a major concern among the PwMS surveyed in the UK. The concern was not about lack of equipment but rather the quality of equipment, the length of time it took to obtain it, the lack of service and maintenance on the equipment, and the lack of training on how to use it. Concerns were not just for individual or home equipment

but also for equipment in hospitals and doctors' offices.

Information Needs

A consistent theme has emerged across studies with PwMS about the discrepancy between the amount of information they have received about their disease and the amount of information they desire. Failing to receive appropriate and desired information may lead to deterioration of the patient/provider relationship resulting in inadequate disease management and doctor changing (Bishop & Frain, 2007; Golla et al., 2011). This gap in what patients and providers view as important information throughout the provision of services is consistent across studies (e.g., Forbes, While, & Ullman, 2006; Robinson, Hunter, & Neilson, 1996).

Classes and continuing education webinars or manuals help many professionals and family members keep abreast of current happenings in the MS field (Defriez et al., 2003). Unfortunately, many PwMS and their families indicate that they are unaware of available resources or how to access them and only come upon a community resource by happenstance (Edmonds et al., 2007)

The desire for accurate information is clearly documented in the literature as a primary unmet need for PwMS. In assessing the information needs of PwMS, Baker (1998) interviewed 13 people with MS who had recently experienced an exacerbation and identified the need to know what medications they were taking and why along with potential side-effects. Further, PwMS want "honest and realistic information that is tailored to their specific needs" rather than generic information about the disease and its management (Baker, 1998, p. 116; MacLean & Russell, 2005). Lorefice et al. (2013) interviewed 497 PwMS and found that although many of them were satisfied with

their diagnosis, most patients and caregivers, 76% and 78% respectively, reported that they left their provider's office lacking a clear understanding of MS and what to expect and subsequently had to search for additional information on their own.

As reflected in these studies, PwMS want and need understandable information about MS and its progression (Galushko et al., 2014; MacLean & Russell, 2005, Ytterberg et al., 2008); symptoms and management options (Forbes et al., 2007; Hepworth & Harrison, 2004 Holland et al., 2011); outcome expectations, including general and individual prognosis (Buecken et al., 2012; Kersten et al., 2000; Koopman et al., 2006); available treatment options; and ancillary service options (Galushko et al., 2014; Oeseburg et al., 2004).

Additionally, PwMS want information on current research (Egger et al., 2012; Hepworth & Harrison, 2004); and insurance and vocational rehabilitation (Ytterberg et al., 2008).

In a study that included roughly 6,000 PwMS obtained from multiple databases, Holland et al. (2011) analyzed the needs of PwMS, in particular those with primary progressive MS, their families, and the healthcare community. The results of that study echoed those of Baker (1998) in that PwMS need better dissemination of information regarding the disease especially on "treatment strategies and support services available to manage it" (p. 68).

Hepworth and Harrison (2004) surveyed 2,030 PwMS in the UK and reported that the provision of disease specific MS information was inconsistent among participants. Specifically, PwMS reported they were not provided information on how to deal with commonly experienced challenges such as balance, bowel and bladder problems, pain, fatigue and, memory difficulties. Hepworth and Harrison further reported that the quality of information

provided was often poor, as a result of what the authors posited to be “general ignorance about the disease among both healthcare professionals and general public” (p. 54). Further, Hepworth and Harrison also investigated the preferred medium of information delivery among PwMS, and for individuals who were between 40 and 60 years old, face to face contact, printed media such as leaflets, and newsletters and magazines were preferred over electronic media such as the internet. Bishop, Frain, Espinosa, and Stenhoff (2009) reported similar findings. In a subsequent needs assessment, MacLean and Russell (2005) noted that PwMS preferred information to be provided in various formats, by different personnel, and preferably in a one-stop setting. MacLean and Russell (2005) and Baker (1998) reported that the content of the information was not the only issue for PwMS, but delivery of information in a personal and empathic manner was also desired. Similar findings were obtained by Buecken et al. (2012) who found that out of the 573 people with MS that they surveyed in Germany, 76% indicated that it was important for their doctors to provide them with individualized information on the progress of their disease, including mortality data.

Transportation, Home Care, and Financial Needs

Transportation and Mobility

Available and accessible transportation affords individuals mobility and the ability to maintain active participation in various life areas (e.g., healthcare, employment, and social events; Syed, Gerber, & Sharp, 2013). The lack of transportation is a particularly salient issue for individuals with disabilities, who are twice as likely as those without disabilities to have inadequate transportation (National Council on Disability, 2005;

Saunders, Leahy, McGlynn, & Estrada-Hernandez, 2006).

The lack of transportation is a critical unmet need for PwMS. Roessler et al. (2013), in a national analysis of Americans with MS, found that the shortcomings of public transportation were noted by many participants, and noted that even participants with the ability to drive reported ongoing concern about what would happen when driving was no longer an option.

Additionally, many mentioned the prohibitive cost of public transportation on a fixed income and characterized public transportation as inefficient and unreliable. Further, public transportation was frequently described as inaccessible, due to a lack of lifts and ramps and the distance of access points from one’s home. These results are consistent with the prior findings of Roessler et al. (2003) in survey research assessing the employment needs of 1,300 patients with MS, in which 94% of respondents viewed transportation as a primary concern while only 36% were satisfied with their current transportation options. Clearly, the lack of available and accessible transportation remains a barrier for PwMS and precludes or impacts their participation in a number of important life activities, including healthcare.

Home Care

Unmet home care needs were identified in seven studies. Included in the category of home care needs were personal care, housekeeping, home help, and care attendants. Patten et al. (2012) surveyed 245 patients with MS drawn from 22,513 census respondents who identified themselves as having health related impairments in the 2006 Canadian national census.

Respondents were asked to indicate whether they were receiving help with their activities of daily living, and if so, their satisfaction with those services. PwMS reported a

significantly higher proportion of unmet needs in this category than those with other diagnoses. Specifically, they indicated needing help with household chores such as cleaning and laundry, shopping, and meal preparation. Approximately 90% of PwMS reported receiving either no help or inadequate help with these activities.

Out of the ten perceived needs that emerged in MacLurg and colleagues' (2005) survey of people with mild, moderate, and severe MS, 30% of the participants reported needs for home help, care attendants, and incontinence services. Similarly, Borreani et al. (2014) found that performing activities of daily living (e.g. personal care, hygiene) emerged as a primary need, with most participants reporting needing help with issues relating to bowel and bladder difficulties. Galushko et al. (2014) also found that PwMS highlighted home care services as essential in enabling them to remain in their homes, and a need for individualized service schedules. The need for home care services was also recognized by nurses and social workers in an analysis by Golla, Galushko, Pfaff, and Voltz (2011), particularly among PwMS in urban areas who live alone and lack social networks.

Financial

Three of the reviewed studies indicated unmet financial needs. Strupp et al. (2012) analyzed 1,100 questionnaires completed by patients severely affected by MS and reported that a significant percentage (31%) of respondents indicated unmet needs in financing of services. Accordingly, the authors concluded that unmet financial needs significantly contributed to how individuals view the severity of his/her MS. Further, unmet financial needs were also reported by participants in Kersten et al. (2000) and Oeseburg et al. (2004) as significantly affecting the ability to obtain treatment, rehabilitation services, and

equipment. Notably, in the study by Kersten et al., financial needs were reported as the primary unmet need by caregivers of PwMS.

Discussion

In this review we have summarized the most frequently identified healthcare and rehabilitation needs of individuals with MS based on a comprehensive review of the literature. Although we have emphasized that the impact and experience of living with MS are different for each individual, in this review we have identified needs that have been found to be common across studies and groups of people with MS internationally. We have framed the needs in the broad context of healthcare and rehabilitation, because this context is the most comprehensive and relevant framework for these most frequently identified needs. Indeed, even those needs that appear to have a more general relevance, such as transportation and finances, are primarily described in the context of accessing and affording healthcare and rehabilitation.

It is not our goal, based on the varying structures and methodologies of the reviewed articles, to prioritize the needs identified. It is clear, however, that some needs were identified with greater frequency across the reviewed articles. Healthcare needs were broad and diverse, and were generally the most prevalent. In particular, information from healthcare providers and about healthcare was frequently identified as an area of high need. This includes information about treatments, including information about medication options and side effects, treatment options, information about prognosis and the potential impacts of MS on future functioning. In addition, people with MS have clearly and consistently expressed a need for reliable, understandable, and relevant information, specifically addressing their situation, rather

than general information about the disease and its management (Baker, 1998; MacLean & Russell, 2005). As noted, it has been observed in several studies that people vary in the manner they prefer to receive such information depending on characteristics such as age.

The need for emotional and psychological support, particularly around the time of diagnosis, was also among the most frequently identified needs. This included the need for several forms of support, including educational support in learning about MS and in preparing for and coping with role and functional changes, social support, caregiver support, and support with staying and feeling productive and in control. And the need for support was also identified as coming from a variety of sources, including healthcare and rehabilitation professionals. Financial support needs and home care needs were also frequently reported across the literature.

The more important point, however, is that each of the 11 categories of needs identified are prevalent among PwMS and their families and caregivers, and that all of these areas require additional and more focused research and practitioner attention. The use by healthcare and rehabilitation professionals of a more comprehensive or holistic approach to evaluating and addressing each of these frequently identified areas of need is indicated. While resources are frequently available to address informational, financial, and emotional support needs, if healthcare and rehabilitation professionals are not asking their patients about their needs, then the patients are not going to be made aware of such resources.

Future Research

It is critical that those involved in the care and rehabilitation of individuals with MS consider the entire range of needs of

those PwMS they serve. In order for this to occur, increased awareness of and research attention to the perspectives and experiences of those living with MS is necessary.

Historically, researchers and clinicians have been primarily responsible for identifying and describing the needs of PwMS. The literature suggests that the opinions of the most important stakeholders (i.e., PwMS) are infrequently considered. Several national and international bodies have, in the past decade, identified the importance and clinical benefits of patient involvement in health care, and research and professional consensus suggest that health care is more effective when consumers are active participants in its design and delivery (Institute of Medicine [IOM], 2001; Kaplan, Gandek, Greenfield, Rogers, & Ware, 1995; Lerman et al., 1990; National Institute for Clinical Excellence [NICE], 2004).

Increased attention to patients' needs by caregivers promotes such engagement and participation. In the past two decades, the number of studies based on this perspective has increased, but the relative infrequency of such research compared with other chronic conditions underscores the necessity of increased and ongoing attention, and it is critically important that such research continue and expand.

Particularly necessary from a research perspective is the further exploration of the needs of specific groups of PwMS, such as those with progressive MS, those recently diagnosed, and those with more significant functional impairment. It will also be increasingly helpful as needs researchers increasingly identify and employ models for organizing the needs of individuals with MS, such as, for example, the World Health Organization's International Classification of Functioning, Disability, and Health (ICF, World Health Organization, 2001) in order to enhance communication and the ability to

compare needs across groups and internationally.

Conclusion

Multiple sclerosis is a complex condition that, by its nature, affects each individual differently. However, as a group, there are healthcare and rehabilitation needs that appear to be consistently identified by PwMS internationally as being unmet. In this paper we have summarized current research on these needs, and identified those that are most frequently identified. Despite the prevalence of MS globally, research attention to the healthcare and rehabilitation needs of PwMS is relatively short-lived and there is a clear need for additional research in this area. This research will be increasingly useful as it leads to more informed and comprehensive assessment in healthcare and rehabilitation settings, and the development of practices and resources that better address these needs.

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