

Advocacy in Multiple Sclerosis

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prepared by:*



THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS



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Advocacy in Multiple Sclerosis

Introduction

Multiple sclerosis is a chronic, frequently debilitating, neurological disease of the central nervous system. It has significant impact on all aspects of patients' and families' lives, including physical, economic, psychological, and social factors. The unpredictable course and related physical and cognitive complications of MS mean patients may experience problems obtaining employment, encounter difficulties in the workplace, strain family and personal relationships, and must challenge insurance company denials and delays for access to appropriate medical equipment, assistive technology, specialists, and psychological support. MS increases financial stress, particularly for low-income and unemployed patients and places additional pressure on family, friend, and peer relationships. It can also result in reduced quality of life (Neri & Kroll, 2003). The multidisciplinary MS care team must be sensitive to these wide-ranging issues, and be proactive patient advocates to ensure optimal quality of comprehensive care. Advocacy can help to ensure that patients' needs and wishes are taken seriously and their best interests are put first (Schwartz, 2002).

Current Practice – Literature Review

To advocate is “to act for, plead, or defend another” (Mitchell & Bournes, 2000, p. 205). Patient advocates work to ensure that effective, safe, high quality healthcare is available and can be obtained in a timely,

cost-effective manner. They work to promote the patient's voice, through empowerment, improved communication, delivery, and access (French, Gilkey, & Earp, 2009). Patients with complex or serious diagnoses, such as MS, are frequently at a loss when faced with a convoluted healthcare system that includes many rules, difficult-to-understand terminology, and complicated administrative processes. Advocates are an integral part of the care team. They provide additional support to ensure that practitioners know patients' treatment wishes; they also educate and explain medical issues to patients. Schwartz noted that advocates encourage informed consent, empower the patient and protect his or her independence, safeguard patients' rights and authority, especially when they are unable to do so on their own (2002, p. 38).

Because MS involves multidisciplinary care for the patient, successful advocacy efforts call for a team effort involving all healthcare disciplines related to a patient's care. Any member of the MS team, including physicians, nurses, social workers, family members and professional patient advocates may take on an advocacy role (French, Gilkey, & Earp, 2009). As advocates, MS healthcare providers must act as problem solvers and often become the link between the patient and health system. They may mediate among family, practitioners, insurance companies, government agencies, and the hospital or healthcare institution. In addition, rehabilitation professionals advocate effectively for patients, particularly if they remain current with the most up-to-date medical treatments (Johnson et al, 2004).

Advocates must be skilled go-betweens, educators, troubleshooters, negotiators, and proactively vocal in tricky situations. In the role of patient advocate, the healthcare team member must walk a fine line

between paternalism and interest protection. Respecting patients as partners, and promoting their perspective is an essential part of advocacy (Mitchell & Bournes, 2000). Advocates must make sure that patients have the knowledge necessary to realize self-sufficiency, ensure that their ethical and legal rights are maintained, and that they receive complete, appropriate, and high quality care (Hyland, 2002).

Barriers to Progress

Numerous issues on the policy, system, and individual levels present roadblocks to optimal patient advocacy. At the policy level, disparities in care and access, as well as obstacles such as education, geography, and insurance coverage impact the quality and continuity of patient care (Neri & Kroll, 2003). For example, in the United States, the lengthy waiting period and application process for Social Security Disability Insurance leaves many patients in limbo for as long as 24 months. The U.S. Social Security Administration has been slow to consider effects such as fatigue or cognitive impairment components of MS-related disability criteria. Similarly, Medicare has not yet approved equal access to all disease-modifying therapies in MS or to orphan drugs for patients with similar rare disorders. In other countries such as Canada, there are also delays in therapy coverage and access to care in spite of a publicly funded healthcare system.

Workplace barriers may affect employment and financial security. These barriers may include an employer's noncompliance with government legislation such as the Americans with Disabilities Act in the U.S. or the Employment Equity Act in Canada. Physical barriers and perspectives

of employers, professionals, and the community are significant roadblocks to employment for people with MS (Johnson et al, 2004). Additional considerations for employment include the type and severity of MS; effects such as fatigue, changes in cognition or communication, depression, pain, bowel and bladder dysfunction, mobility limitations, or spasticity can impact productivity and absenteeism. Advocates can assist with promoting interventions to manage and accommodate varied symptoms in the workplace.

Improper or delayed access to healthcare impacts financial status, leads to greater risk of secondary complications, deterioration in health status, hampers mobility and activity, affects the ability to hold a job, and leads to depression, stress, and frustration on the part of the patient (Johnson et al, 2004). Patients may not have the means or ability to address the complexities of the current health system. Patient advocates help to ensure continuity of care and act as a bridge between providers and patients. Advocates assist patients with access to specialists or other health professionals, and negotiate work, financial, legal, or other issues (Brody, 2009). Barriers are not isolated issues but intertwine to affect many aspects of patients' lives. For example, social costs encompass interactions with family, friends, and co-workers, changes in current social roles, and limits in community participation (Neri & Kroll, 2003). Advocates need to be adept at managing multiple concerns to benefit the best interests of the patient.

Application to MS Healthcare Community

Throughout the world, approximately 2 million people have multiple sclerosis. The Multiple Sclerosis International Federation (MSIF) notes

the many issues that affect MS patients worldwide include lack of social support; lack of education about MS; lack of access to various therapies; employment issues; and concerns regarding health insurance and social security. To increase awareness of and to promote these issues, the MSIF organized a “World MS Day” which takes place every year at the end of May. Advocating for the rights of people with MS is one of the goals of the World MS Day (MSIF, 2009).

Generally, advocates for MS patients are involved in myriad issues – including healthcare access and delivery, disability benefits, workplace and housing accommodations, family and personal relationships, as well as policy matters at the community, local, and national levels. Researchers report that patients with disabilities (including, but not limited to MS), are concerned about access to timely and appropriate healthcare services, specialists, medical equipment; lack of transportation; obtaining technology; limited education; employment and workplace issues; lack of community-based long term care; and obtaining and relying on public assistance and government benefits (O’Day & Goldstein, 2005).

As with other chronic diseases, patients with MS depend heavily on the healthcare system and public support. People with MS who are unable to work often rely on government programs for financial aid, disability benefits and cash assistance (MSIF, 2009). A 2007 random survey by the National Multiple Sclerosis Society (NMSS) in the U.S. showed that 21 percent of patients cut back on food, heat, or other essentials to pay for healthcare; 22 percent did not fill prescriptions or skipped medication because of cost (NMSS, 2009). Healthcare providers are often called upon to help patients seek out the maximum entitlement. They also frequently

campaign on the patient's behalf to get the range of benefits needed, such as disease-modifying therapies, durable medical equipment, adaptive technology, or personal assistance. Advocates and health professionals must be aggressive to assist patients in getting the most current therapies (Johnson et al, 2004).

Unemployment and lack of workplace accommodations for people with chronic illnesses and disabilities are pervasive problems. Within five years of receiving an MS diagnosis, the majority of patients are unemployed (Johnson et al, 2004). Many with the disease stop working well before they had planned. This has consequences for many aspects of their lives, especially economically. Advocates can help to educate patients and employers about rights and responsibilities under human rights legislation, and help to negotiate workplace accommodations, correct myths and misconceptions about MS, and ensure that opportunities exist for the worker to remain productive (Johnson et al, 2004). To alleviate unemployment, there is also a need for better education, skills training, and job preparation for those with disabilities. More needs to be done to decrease reliance on government benefits, which frequently pose a catch-22 scenario due to work disincentives. Availability of equipment and adaptive technology, and effective leveraging of available resources will benefit the MS community by helping to ensure that employment and community participation is possible (Johnson et al, 2004; Multiple Sclerosis Coalition, 2009; O'Day & Goldstein, 2005).

Low-income, and low-income minority patients with MS may be most in need of patient advocacy. They experience the majority of problems obtaining healthcare and therefore have poorer outcomes (Shabas & Heffner, 2005). Many experience suboptimal continuity of care and

frequently develop avoidable secondary complications. Patient education is spotty, and there are often language and cultural barriers to overcome as well. Low income status impacts all aspects of patients' lives, including education, lack of transportation, insurance status, housing, technology, and social involvement (O'Day & Goldstein, 2005). Insurance status in the U.S. limits access to specialty care, which is important for proper diagnosis and evaluation, symptom management, and prevention of complications. Care by MS specialists has been correlated with greater probability of patient knowledge about and adherence to disease-modifying therapies (Shabbas & Heffner, 2005). The authors noted that low income, lack of education, poverty, and public insurance coverage posed considerable obstacles to first-rate care. Therefore, it becomes even more important for the patient advocate to step in and assist with referrals to specialists, alleviate insurance issues, and enhance patient education.

Best Practices and Consortium of Multiple Sclerosis Centers (CMSC) Recommendations

In order to be an effective advocate, all healthcare professionals need to stay current on the latest changes in both medical treatment and public policies related to MS. This will help to support patients' rights to autonomy and independence. Improved knowledge of access difficulties will help prevent expensive and negative repercussions for MS patients, and for the community, which often must pay for these results (Neri & Kroll, 2003). A key role for patient advocates is to educate healthcare professionals, employers, the public, bureaucrats, and insurers on the challenges and issues associated with disabilities so they can more effectively treat and interact with disabled patients.

Many current issues associated with disability can be improved through patient advocacy that works to eliminate environmental and physical constraints, social stigma, and improved public policies that foster an approach of self-sufficiency and empowerment. Several current strategies, such as coalition building, patient and stakeholder education, and legal challenges have proven successful and should be continued. (O'Day & Goldstein, 2005).

A leader in advocacy efforts is the MSIF, an organization that links national MS societies from around the world. The MSIF seeks to improve the lives of people with MS worldwide with advocacy efforts focused on public policy. In the document entitled "Principles to Promote the Quality of Life in People with Multiple Sclerosis," the MSIF calls for legislation "that protects the rights of people with MS and other people with disabilities against discrimination in all aspects of social and community life" (MSIF, 2009, p. 22).

By partnering with other groups with similar interests and goals, patient advocates can increase their effectiveness and reach. For example, the Multiple Sclerosis Coalition (MS Coalition) currently includes nine independent multiple sclerosis organizations working to benefit individuals with MS. The MS Coalition collaborates to ensure support and funding for MS research, programs, and awareness. A unified approach achieves far greater impact on critical public policy initiatives than each of these organizations could achieve individually. MS Coalition members also seek to ensure that affordable, comprehensive healthcare and therapies are available to all patients.

It is important to remember the essentials of patient advocacy: valuing patients' rights to self-determination; educating and advising patients so they may fully participate in decision-making; mediating between patients and others, including practitioners and family members, to ensure that the patient's desires are respected (French, Gilkey, & Earp, 2009). Participation in cross-disability movements will help to build a stronger, more encompassing campaign to address common issues such as access, insurance coverage, and civil rights. Building alliances with government leaders on disability issues will also help to establish and maintain a strong political base and increase the advocate's understanding of the political process (O'Day & Goldstein, 2005).

MS Coalition members include: Consortium of Multiple Sclerosis Centers (CMSC), International Organization of Multiple Sclerosis Nurses (IOMSN), Accelerated Cure Project For Multiple Sclerosis, Can Do Multiple Sclerosis (formerly The Heuga Center for Multiple Sclerosis), Multiple Sclerosis Association of America (MSAA), Multiple Sclerosis Foundation (MSF), National Multiple Sclerosis Society, United Spinal Association, and The Vision Works Foundation, Inc./MS Friends Initiative. Each member lends expertise and knowledge to inform stakeholders, promote change, and improve quality of life for those with MS.

Details about the MS Coalition may be found at

www.ms-coalition.org

CMSC Recommendations

The Consortium of Multiple Sclerosis Centers and its members are involved in many activities that support patients and their families. Our goal is to help these individuals sustain a full and rich quality of life while living with MS. In our unique position as the pre-eminent international organization of MS care professionals, we speak as one voice on behalf of patients and their families. For continued efforts in patient advocacy, the CMSC recommends:

- Partnering with existing established organizations in their advocacy efforts (e.g MS Coalition, National Organization for Rare Disorders (NORD), American Brain Coalition (ABC), One Voice Coalition (a committee of the American Academy of Neurology) and MSIF.
- Developing and implementing mechanisms to influence healthcare delivery (e.g. support public policy recommendations from the MS Coalition, the MSIF and other advocacy partners, support legislation, etc.).
- Collaborating with MS groups to promote public policy that results in fair access and appropriate services and therapies to people with MS worldwide.
- Stay in touch with advocacy issues by visiting the MS Coalition website (www.ms-coalitionmultiplesclerosiscoalition.org) and the MSIF website (www.msif.org).
- Educating CMSC members about advocacy issues and obtaining input from the CMSC membership and the MS community about their concerns; encouraging members to learn about what is needed in medical documentation to support patients' request for disability.

- Continuing to work on the local, state, and national levels to support and enhance:
 - Access to affordable healthcare.
 - Patients' rights legislation.
 - Expansion of health insurance coverage.
 - Affordable long-term care services.
 - Broadening publicly-funded program.
 - More inclusionary pharmaceutical assistance programs.
 - Additional research funding of MS and related neurological disorders.

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