

An Initiative to Improve Care in the Community: Multiple Sclerosis At Home Access (MAHA)

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Background

Despite advances in treating relapsing forms of Multiple Sclerosis (MS), a significant number of individuals have, or will enter, a progressive phase of disease. Previous study found a substantial-to-profound disability in more than one-third of individuals with MS and indicated 36% of individuals with MS were using assistive walking devices. (21% canes and walkers, 15% wheelchairs).¹

Recent estimates of the prevalence of MS in the U.S. total over 1 million individuals, more than twice that of previous reports,² in part suggesting an increasing number of aging individuals with progressive forms of MS.³

- Individuals with disabling forms of MS have varying symptoms most with limitations in: mobility, upper body movement, coordination, bladder and bowel function, vision, speech, swallowing and respiratory musculature.
- Over half have physical pain related to neuropathy or spasticity.^{1,4}
- As disability increases patient-reported health-related quality of life decreases.⁵
- Family members are likely to suffer from caregiver burden, mood disorders, and strain on their health.⁶
- Most desired to remain at home when possible, acknowledging the overwhelming impact of the disease on their family.⁷
- The emotional toll of progressive MS is evident in a strategic MS Society White Paper report. Individuals reported feeling "disconnected," "underserved," "isolated," and "forgotten."⁷

Deficiencies in all phases of access to MS care for those with disability, before, during, and after healthcare visits have been well-documented including:

- Before visits: Insurance, referrals, making appointments, lack of and/or inadequate transportation services.
- During clinic visits: accessibility, including inadequate handicap parking at provider offices, lack of and/or inadequate equipment for examinations, insufficient time with providers, providers' inadequate MS education, poor communication, and lack of general care for those with disabilities.
- Post-visit: difficulty connecting to referrals made at the visit and lack of follow up.⁸

Individuals with progressive forms of MS and disability are exceedingly likely to develop generally preventable complications and comorbidities, along with significantly increased healthcare utilization and costs.

The dynamic, highly complex, and disabling phase of progressive MS with inherent limitations in mobility combined with lack of vital community resources presents extensive challenges in essentially all aspects of healthcare delivery, especially access to health care.

Methods

After 1 year of a house call program serving 21 patients with MS and significant disability (EDSS \geq 7.5) lessons learned included

- Input from patients and families and MAHA Team on regular ongoing basis recording both positive and negative issues and reports were recorded throughout the program during house call visits and weekly team conferences.
- Additional open-format items included in satisfaction with program provided the opportunity to express positive and negative thoughts about the program and recommendations. These surveys were given during the house-call visit collected 3 and 6 months time periods and de-identified.
- Recurrent themes and commonalities were identified and a verification meeting was held for agreement on important lessons learned with anticipated guidance of the future direction of program.

Lessons Learned

Comprehensive in-home assessments increased understanding of the needs of individuals with MS and significant disability	Common observations included problems managing medications, lack of personal care assistants, issues with durable medical supplies, insufficient knowledge for preventing complications related to immobility, along with limited transportation, housing, and finances. Varying dynamic complex social and financial issues persisted for all patients.
Trusted, competent providers mattered	Patients and family members repeatedly reported frustration with the layers of providers and wanted to be able to count on a certain trusted few, familiar with their issues. Attrition of care team members, generally nurses and personal care assistants, disrupted trusting relationships. <i>Persistent</i> care team partners reported increased knowledge and keen awareness of needs and issues of patients with severe disability, suggesting a transdisciplinary team with high expertise was evolving. These <i>persistent</i> team members also unexpectedly became involved in community advocacy for persons with disability, including attending city transportation meetings, conferencing with the Department of Health and Human Services, and developing public awareness material.
Follow through was a critical issue after hospitalization, ER visits, and sub-specialty clinic visits	Frequently, referrals, prescriptions, application forms, etc. were inconsistently completed following clinic visits or hospitalizations. The house-call medical assistant became instrumental in assisting individuals, particularly those with little to no social support by completing paperwork, with stringent follow-up, to secure needed resources. This type of assistance in the long run likely helped reduce preventable complications and greatly contributed to the productive interaction central to this chronic illness model.
Once active problems were stabilized, about 50% of patients were able to participate in tele-visits	Those unable to participate generally had financial and/or support issues/physical limitations in obtaining/implementing the technology. Tele-visits in stable patients with appropriate support were perceived to be very positive. Occasionally technical difficulties were encountered, and phone conversations took place as back up.
Substantial assistance with ADLs and IADLs was a consistent need in virtually all persons with an EDSS > 7.5	The integration of a compassionate, competent, informal caregiver/personal assistant (with the goal of a waiver in lieu of nursing facility placement) "made all the difference in the world" to patients and families.
Lack of adequate transportation and housing for those with severe disability was a critical issue	Seventy percent of the program participants were outside of the paratransit corridor and had no consistent wheelchair-accessible transportation. Low-income ADA housing, especially in the paratransit corridor was difficult to find, and several patients seen in our program had inadequate and/or unsafe housing.



Conclusions

Lessons learned, and insights that emerged over the first year of operation, identified by patients, family members, and providers providing valuable direction for our program.

Key findings included benefits of assessments in homes, importance of clinical expertise and continuity of care, close follow up, need for greater assistance with ADLs, benefits of supplemental tele-visits, and greater awareness of societal limitations for the disabled, including transportation and housing.

Persistent team members un-expectantly became community advocates for persons with disability.

Most individuals expressed a desire for integration back into the community but were unable to obtain appropriate transportation and lack financial resources

Individuals residing at home with disability as a group were/are talented, tenacious and fiercely "dependently independent."

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