

Advanced Practice Clinicians' Assessment of Care Strategies for Multiple Sclerosis Care

Lee J,¹ Mayer L,² Moore M,³ Namey M,⁴ Smith J,⁵ Butts D,⁶ DeBusk K,⁶ Knight J⁷

¹Stanford Healthcare, Palo Alto, CA; ²MS Clinic of Central Texas, Austin, TX; ³MS Center of Carolinas Medical Center, Charlotte, NC; ⁴Cleveland Clinic, Cleveland, OH; ⁵Oklahoma Medical Research Foundation, MS Center of Excellence, Oklahoma City, OK; ⁶Biogen, Boston, MA, ⁷Xcenda, Palm Harbor, FL

Consortium of Multiple Sclerosis Centers
2016 Annual Meeting
Jun 1- Jun 4, 2016
National Harbor, MD

INTRODUCTION

- Multiple sclerosis (MS) is a chronic disease that causes a wide array of symptoms and impacts various aspects of patient functioning.
- Care practice algorithms are disseminated by various multiple sclerosis (MS) care organizations, but tend to focus on pharmacological treatment selection and are mostly used by physicians.¹
- Establishing best practices for holistic MS patient care is a challenging endeavor for Advanced Practice Clinicians (APCs) due to the numerous and complex clinical and social factors that these health care professionals need to consider when caring for patients with MS.
- A need exists for a holistic approach to care management with a focus on both patients and caregivers.

OBJECTIVES

- Identify the most important unmet needs for MS patients.
- Define individual factors that APCs consider when caring for MS patients.
- Assess visual patient care models that identify multidisciplinary care team members.

METHODS

- An MS Care Strategies Steering Committee comprised of APCs designed a 49-question survey to better understand the complexity of caring for patients with MS and to develop a consensus-driven holistic model of care.
- The online survey was sent via email to all (~1000) members of the International Organization of MS Nurses (IOMSN) between June 29, 2015 and August 3, 2015. Participants were not reimbursed for their participation.
- The survey content focused on 11 common unmet needs in MS care and 79 care inputs to consider when caring for patients with MS. Survey respondents were asked to assign the care inputs into 3 broad categories: Patient Profile, Disease Course, and Other Care Considerations. Consensus was defined as ≥ 50% of respondents assigning a care input to a category.
- The committee developed 3 MS patient care models to represent multidisciplinary care teams. Survey respondents rated the relevance of the 3 models across 7 attributes on a scale from 1-7; 1 is extremely negative and 7 is extremely positive.
- Descriptive analyses were used to characterize the survey results.

RESULTS

- Thirty respondents completed the survey (response rate: ~3%). The majority of respondents identified themselves as MS Certified and/or Registered Nurses (90%) and reported working in an MS Center of Excellence (70%).

Unmet Needs in MS Care

- Mental health consultation and treatment, respite care for caretakers, and cognitive remediation therapy were ranked as the top 3 unmet needs in MS care (Figure 1).

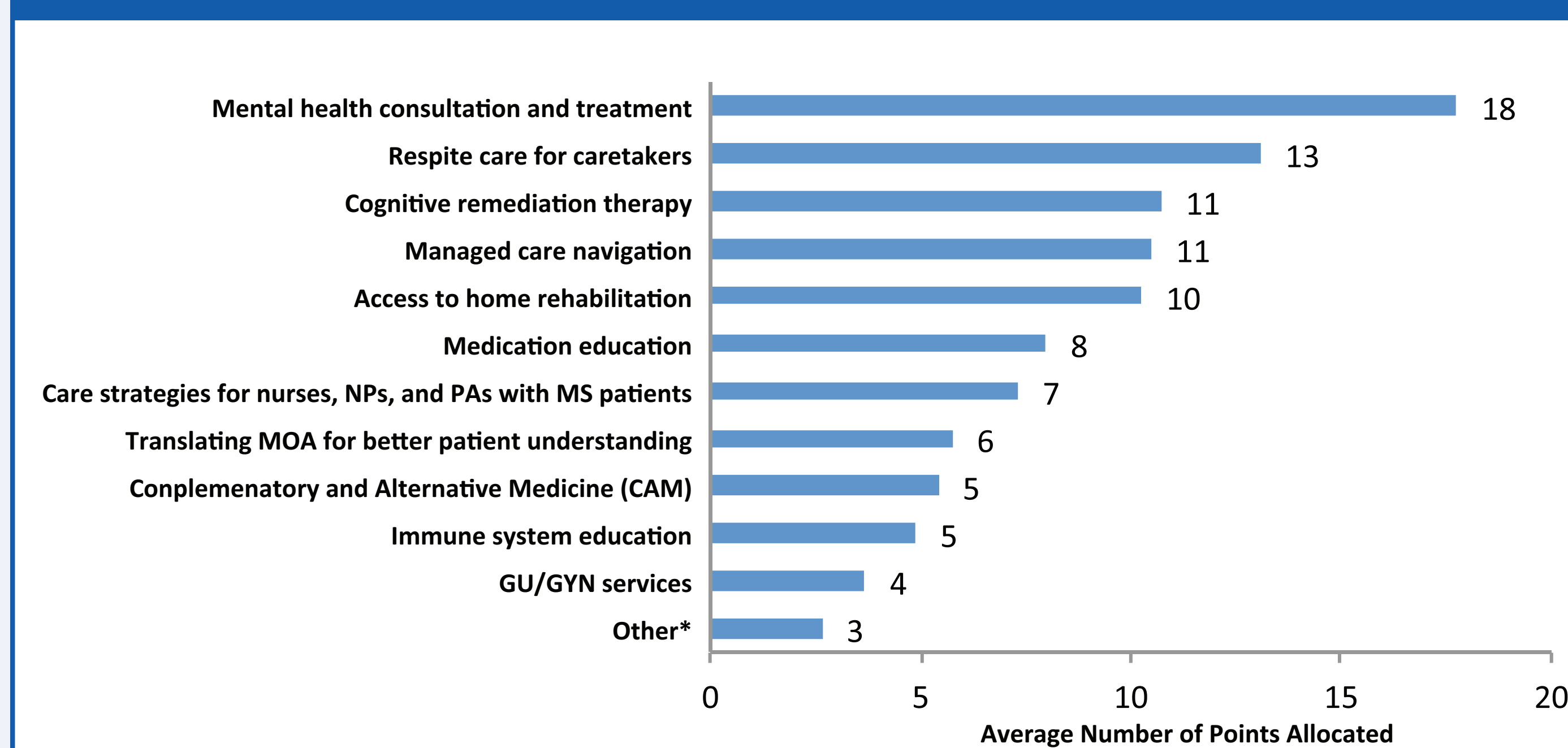
Care Input Category

- There was consensus among 75 of the 79 care inputs (95%) across all patient care categories (Tables 1-3).

MS Patient Care Model Evaluation

- A majority of the survey respondents (67%, n=20) had moderate to extremely positive impression of the MS Patient Care Model 1 that focused on the patient and their family, emphasizing the fluidity and interconnectedness of the multidisciplinary MS care team (Figure 2).
- Survey respondents rated MS Patient Care Model 1 as “moderately positive” for 6 of the 7 attributes in the survey. The highest rated attribute for MS Patient Care Model 1 was “easy to interpret” (average rating: 5.67), followed by “relevant to my practice” and “easy to explain” (average rating 5.60).

Figure 1. Unmet Needs in MS Care Ranking (N=30)



*Respondents who allocated points to “Other” had the option to write-in a response. Responses included: access to medications, finances, future planning, continued education and support for patients and families, knowledge, time and resources, nurse navigator specific to their clinic, and case management resources.

Table 1. Categorization of Patient Profile Items (N=30)*

Health History	Patient Factors
Family History of MS	Age
Comorbidities	Ethnicity
Surgeries	Body Mass Index (BMI)
Vaccinations	Geographic Location (e.g., urban, rural, proximity to an MS Center)
Environmental Exposure (e.g., heavy metals/chemicals)	Occupation
Allergies	Children/Dependents
Medication History	Education
	Religion
	Marital Status
	Children/Dependents
	Mental Health Status (e.g., mood)
	Risk Tolerance
	Substance Use (i.e., illicit drugs, alcohol, tobacco)

*One care input did not achieve consensus: Polypharmacy (47% in ‘health history’)

Table 2. Categorization of Disease Course Items (N=30)

Clinical status	Prognostic factors	Paraclinical markers	Treatment	Adherence	Pregnancy
Cognitive Status	Age at diagnosis	Cerebrospinal fluid (CSF)	Disease modifying therapy (DMT) response	Non-adherence factors	Pregnancy status
Form of MS (Relapsing vs Progressive)	Age	Varicella-zoster virus (VZV) antibody	DMT history (e.g., tried and/or failed)	Adherence history	Future family planning
Post-Relapse Recovery Status	Gender	Neutralizing antibody	Treatment status (naive vs experienced)	Tolerance	
Disability	Race	Tysabri antibody	Mechanism of action (MOA)	Needle aversion	
Disease Activity	Relapse Frequency and Severity	Vitamin D status	Adverse event symptom management		
Comorbidity (e.g., mental health, urology)	Magnetic resonance imaging (MRI) data	John Cunningham virus (JCV) antibody status	MS symptom management		
		Optical coherence tomography (OCT)			

Table 3. Categorization of Other Care Considerations Items (N=30)*

Barriers to patient care	Patient functioning	Alternative medicine options	Financial issues	Educational factors	Values and beliefs	Social support	Community resources
Language	Activities of daily living	Complementary and alternative medicine	Economic	Health literacy	Acceptance/ hope	Family support	Mental health resources
Access to care	Mobility		Insurance	Knowledge of MS	Patient's health belief model	Care-partner needs	Access to specialized resources
	Exercise				Spiritual beliefs		Long-term care needs
	Nutrition				End of life issues		Nursing accessibility
	Engagement and self-sufficient				Cultural		
					Quality of Life		

*Three care inputs did not achieve consensus: Legal Issues (46% in ‘barriers to patient care’), Patient/Provider Relationships (30% in ‘barriers to patient care’), and Hobbies (30% in ‘patient functioning’)

Figure 2. MS Patient Care Model 1



CONCLUSIONS

- There is substantial agreement on aspects of care that is important when treating patients with MS from the APC perspective.
- Caring for a patient with MS is multifaceted and can be conveyed visually to patients and APCs to simplify its complexity.
- Future work should validate the care inputs with patients and ensure that the model represents their experience. Such a model may enable patients with MS to better communicate their needs to their care team, potentially resulting in overall better treatment outcomes for patients and their families.
- Greater importance must be given to providing a continuum of care that includes an interdisciplinary team approach and promotes quality comprehensive care for patients with MS.

LIMITATIONS

- Given the low response rate, findings from this study may not be generalizable to all APCs. Future research should attempt to replicate the findings.

References

- Ford C. Therapeutic Decision Making in Multiple Sclerosis: Proceedings of a CMSC Consensus Conference. *Int J MS Care*. 2014(16):6: 13.

Acknowledgments

This research was funded by Biogen, Cambridge, MA, USA. Poster presented at the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting on June 1-4, 2016 at National Harbor, Maryland.

