Understanding the Unmet Needs of Patients with Multiple Sclerosis

Dr. Christine Leithead DNP, RN & Dr. Molly J. Bradshaw DNP, FNP-BC

Rutgers, the State University of New Jersey

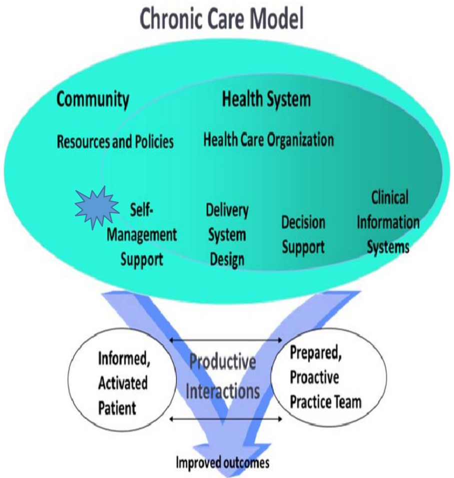
INTRODUCTION

Patients with Multiple Sclerosis (MS) need individualized care specific to their disease process. Healthcare workers, caregivers, and the patients are challenged to provide care while preserving quality of life. Within the literature, Multiple Sclerosis patients have communicated needs that are unmet. These include needs such as a cure, education, care coordination, access to care, financial support, and strategies for symptom management (Mehr & Zimmerman, 2015; Litchfield & Thomas, 2010; Heesen, Kopke, Richter, & Kasper, 2007; Galushko et al., 2014; Smyth, 2011; Lonergan et al., 2015). Understanding the needs of the Multiple Sclerosis patient can be accomplished through identification of the unmet need(s), open discussion about the need(s), and focusing collective efforts of the healthcare system, families, and individuals to meet those needs.

Key words: Unmet Need, Multiple Sclerosis, Community

PURPOSE AND FRAMEWORK

The purpose of this systematic review is to identify and articulate unmet needs of multiple sclerosis patients. Describe self-management strategies for the symptom of fatigue as it relates to the Chronic Care Model.



Barr, et al., 2002

METHODS

Using the Joanna Briggs Institute methodology for qualitative systematic review, the literature was originally searched to explore the lived-experience of MS and attempt to catalog unmet needs of patients in the outpatient, community based setting.

Unmet Need: "any need, or requirement for care, that the patient perceives as not being adequately met by healthcare providers, the healthcare system, family, social networks or the community."

Participants: Patients diagnosed with MS at any age and in any pattern of the disease existing in the outpatient setting

- Qualitative Studies
- Patient Voice
- Initial Databases: MEDLINE, PUBMED, CINHAL
- 27 results

JBI: Conditional approval of study protocol with clarification needed of inclusion criteria and definition of unmet needs. Librarian review in all databases resulted in 558 results that were hand searched.

REFOCUS: Self-Management Support for Fatigue

- Qualitative Studies
- Patient Voice
- Initial Databases: PUBMED, CINHAL
- 48 results

PROPOSAL RESUBMITTED

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PRELIMINARY RESULTS

A precise systematic review cataloging, defining, and articulating a list of comprehensive self-management strategies for fatigue has not been identified. Prior to revision of the search strategy, patients articulated that their needs are unmet.

Improved Medical Home

"It would be nice to have someone that knew you and knew what you were going through…to understand your symptoms and say, 'okay, this is your next step, this is your next step,' And traditionally I think this was the role of primary care, but I swear once you get MS your primary care is just like, 'Oh, it's MS.'"

"Well, I have different symptoms and I feel like a ping-pong ball. You have this? Go here. You have that? Go there. And no one is putting it all together to make sense of things…It's frustrating because you feel like your always missing a piece of the puzzle, like there's something not quite coming together."

Lack of Self-Management Strategies

"I think that's one of the problems with MS, they do too much research on medication and not enough on other alternative therapies for people with MS. Like diet makes a big, huge difference, and nobody talks about it…"

"I guess I like to know what the latest research says exercise is doing for people. I didn't know until I came here that people say exercise helps with cognition, so I think my neurologist should tell people that."

"I'm not really sure what I need, I don't know much. Maybe just information. Where to go and what to do."

Lack of Access to Resources

"In this area, what places can accommodate the needs of people with MS? That's the biggest issue."

"It's simply more access, more time at the MS centre to receive help, one day is not enough to service everyone."

"…(help) not available outside of work hours."

ANTICIPATED FINDINGS

Multiple sclerosis patients articulate unmet needs that, if met, would improve self-management of the disease. Since fatigue is the most common symptoms future work on this systematic review will be toward identification of strategies to address this gap.

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***Additional references and JBI protocol available upon request.

CONTACT INFORMATION

Dr. Christine Leithead DNP, FNP, RN
Rutgers School of Nursing
cmleitheadnp@gmail.com

Dr Molly J. Bradshaw DNP, FNP-BC
Associate Professor
Eastern Kentucky University
molly.bradshaw@eku.edu