Living Well with Multiple Sclerosis: A Healthcare Provider Perspective

Susan Schincariol, MOT student; Lindsay Richards, MOT student; Setareh Gahhari, PhD(OT); Susan Forwell, PhD, OT(C), FCAOT
Department of Occupational Science and Occupational Therapy • University of British Columbia, Vancouver, BC, Canada

Background
Persons with chronic conditions, such as MS, play an integral role in the management of their conditions.
Research indicates ineffective self-management skills are related to depression and feeling a lack of control.
Living well with MS involves self-management on a day to day basis that includes:
- confidence and skills for medical, emotional and role management in one’s daily life
- assistance from health care professionals and personal & community supports

Rationale
There is a paucity of research concerning the healthcare providers’ (HCP) perspective of self-management support in MS.
Without an understanding of the facilitators and barriers for the clinicians to support self-management among MS clients it is not clear how these issues might be addressed.

Objectives
1. Explore HCP perspectives related to supporting self-management among clients with MS
2. Develop a preliminary framework to describe practitioners’ perspectives regarding self-management support for clients with MS

Participants
Nine clinicians met the inclusion criteria:
- All were female
- Practicing in either the community or at the UBC MS Clinic

Healthcare Provider Disciplines
- Physician - Neurologist
- Registered Nurse
- Occupational Therapist
- Physical Therapist
- Social Worker

Methods
- Recruitment through
  - UBC MS Clinic
  - MS networking group using snowballing technique
- Eligibility criteria
  - Licensed or registered with professional body
  - Practice includes working with patients with MS

Research Design
- Semi-structured interviews of approximately 15-20 minutes
- Interviews were conducted either by phone or in a quiet location convenient to participants
- Interviews were audio recorded and transcribed verbatim
- Interview questions included:
  - What strategies, information, referrals or advice would you provide?
  - What are some of the barriers or challenges you face when assisting your patients to live well with MS?
  - What are some of the challenges for your patients in living well with MS?
  - What are some of the resources you use?
- Data Analysis
  - Open coding was completed and categories and themes were developed

Results

Strategies, information and referrals HCPs provide when assisting patients to live well with MS
Most reported using “Philosophical Position(s)” including:
- Individualized approach
- Holistic approach
- Multi-disciplinary approach
- Anticipatory approach – cognizant of future needs

Knowledge & Skill Building
- Provide information about disease and community resources
- Communications management/telling others
- Symptom management – education & techniques
- Development of problem solving strategies & skills
- Facilitate navigation of the healthcare system

Psychosocial Skills & Support
- Reframing perspective
- Validating experience
- Support and encouragement – listen & talk it through

Barriers or challenges HCPs perceive their patients have in living well with MS

Symptom Related
- Lack of knowledge about MS and symptoms
- Difficulty with symptom management

Psychosocial
- Depression/lack of motivation
- Isolation
- Loss of identity
- Living with unpredictability
- Anxiety or guilt around treatment decisions

Treatment Related
- Treatment complications such as medication side effects

Personal Resources
- Limited patient income
- Difficulty with employment
- Limited housing options
- Insurance company limitations
- Transportation difficulties

Public Arena
- Social stigma/Difficulty telling others
- Lack of public support and awareness regarding MS
- Limited access to the physical environment

HCP-Patient Relationship
- HCP disbelief in patient
- Poor HCP-patient interactions or fit

Resources that HCPs use to help patients live well with MS
- Long term disability
- Pension plans
- Extended health plan/benefits
- Government/nongovernment organizations
- Health units
- Specialty programs (e.g., MS Clinic)
- Community centres
- Transportation for persons with disabilities
- Red Cross
- MS Society
- Disability foundations
- Consortiums
- Scientific journals/literature
- Internet
- Support groups
- Family support/friends
- Adaptive aids/equipment

HCPs barriers or challenges in assisting patients to live well with MS

Professional Challenges
- Difficult patient situations (e.g., despair, unmotivated)
- Limited scope of practice in clinical settings
- Limited time per individual
- Lack of emphasis on quality of life, not just on health maintenance

System Challenges
- Limited multidisciplinary healthcare resources (availability, quantity and type)
- Limited funding: terminology/designations not “funded” for MS
- Difficulty with insurers, need for advocacy
- Difficulty navigating the healthcare system
- Lack of support resources (e.g., housekeeping, affordable community resources)

Community Related Limitations
- Geographical barriers
- Lack of public support and awareness regarding MS

Conclusions
The strategies, information, referrals and advice that HCPs use to facilitate living well with MS centre around:
- Philosophical position
- Knowledge and skill building
- Psychosocial skills & support

HCPs perceive or have experienced professional challenges, system challenges and community related limitations when providing self-management support.
HCPs identified a number of barriers to their patients living well with MS including:
- Symptom challenges
- Psychosocial factors
- Treatment issues
- Personal resources
- Public arena
- The HCP-patient relationship

Implications
In order to generalize these findings additional research with a larger sample of HCPs is required.

References

Acknowledgments
This study was funded by the Canadian Institute of Health Research (CIHR) Operating Grant # MOP-12883.

Conclusions
The strategies, information, referrals and advice that HCPs use to facilitate living well with MS centre around:
- Philosophical position
- Knowledge and skill building
- Psychosocial skills & support

HCPs perceive or have experienced professional challenges, system challenges and community related limitations when providing self-management support.
HCPs identified a number of barriers to their patients living well with MS including:
- Symptom challenges
- Psychosocial factors
- Treatment issues
- Personal resources
- Public arena
- The HCP-patient relationship

Implications
In order to generalize these findings additional research with a larger sample of HCPs is required.

References

Acknowledgments
This study was funded by the Canadian Institute of Health Research (CIHR) Operating Grant # MOP-12883.