

## Research Paper

# Learning to live with multiple sclerosis cognitive impairment and how it influences readiness for group cognitive intervention

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**Abstract**

**Background:** Up to 65% of people with multiple sclerosis (MS) have cognitive impairment that negatively affects quality of life, social functioning, and work. Evidence is building to suggest cognitive rehabilitation is a helpful intervention strategy, and that a group approach can be effective for individuals with MS. Further exploration of how to maximize the potential of group cognitive interventions is warranted.

**Objective:** To describe how the psychological process of learning to live with MS-related cognitive changes influences participation in a group cognitive intervention.

**Methods:** A qualitative design with interpretive description approach was used to ask consumers with MS the important features of a group cognitive intervention. Ten females with self-reported physician-diagnosed MS participated in two focus groups. Focus groups were audio recorded and transcribed. Inductive analysis resulted in content and process categories and themes.

**Results:** The focus groups echoed the processes and relationships that occur in a group intervention program. The main three themes represented stages in a process of learning to live with cognitive changes. The three themes were: 1) coming to know yourself with cognitive changes, 2) learning to cope with cognitive changes and 3) living a changed life. Relationships exist between these stages and the extent to which an individual will benefit from a group cognitive intervention program.

**Conclusions:** Knowledge of group process and the psychological processes involved in behavioral change are essential skills for facilitating a cognitive intervention group for people with MS. © 2016 Elsevier Inc. All rights reserved.

**Keywords:** Cognitive rehabilitation; Multiple sclerosis; Group process; Behavioral change; Disease acceptance

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Multiple sclerosis (MS) is a common demyelinating disease of the central nervous system.<sup>1</sup> Up to 65% of people with MS have cognitive impairment that negatively affects quality of life, social functioning, and work, unrelated to physical functioning.<sup>2</sup> The cognitive impairment tends to follow particular patterns where certain functions such as language and semantic memory are preserved whereas episodic and long-term memory, processing speed and executive functions are impacted.<sup>3</sup> Thus, it is important to design cognitive intervention programs specifically for individuals with MS.

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Evidence is building on the effectiveness of cognitive rehabilitation for people with MS.<sup>4,5</sup> Cognitive remediation has demonstrated potential for improving performance of specific cognitive domains in psychometric testing, such as memory, following a period of cognitive exercises.<sup>6–8</sup> A recent systematic review recommends further research on the ability of cognitive rehabilitation to impact self-perceived cognitive capacity due to promising results of intervention studies targeting executive functions.<sup>4</sup>

Group interventions for people with multiple sclerosis have had positive results for multiple outcomes,<sup>9</sup> including psychological, social, and chronic disease management outcomes.<sup>10–13</sup> Further, groups for cognitive rehabilitation have been found to be feasible and acceptable to consumers with MS.<sup>11,14–16</sup> Pilot studies of group cognitive interventions have demonstrated improvements in individuals with mild cognitive impairment that interferes with daily functioning<sup>15</sup>; both a self-management approach and a meta-cognitive training program enhanced self-efficacy and awareness of cognitive strategies.<sup>15,16</sup>

Group interventions uniquely address participants' needs through both the content delivery as well as the group process. Group process is the "personal and interpersonal processes that emerge between group participants and between them and the group facilitators."<sup>17(p392)</sup> The group setting allows participants to learn more about themselves, the changes they want to make in their lives, and be supported in making these changes. Groups provide participants with an opportunity to take on both an "expert" as well as learner role as they share successes and struggles with group members.<sup>18</sup> To our knowledge, considering the group process in cognitive intervention groups has not been specifically addressed in the literature beyond knowing that participants value learning from, and being validated by the personal strategies and experiences of others with MS.<sup>15,16</sup>

The purpose of this paper is to describe how individual psychological processes of learning to live with MS-related cognitive changes influences participation in a group cognitive intervention. The larger study objective was to learn what consumers anticipated would be helpful content and format features of a group cognitive intervention that was to be developed for local use. Since the literature has already identified some content and structure features that consumers find helpful in a group cognitive intervention,<sup>15,16</sup> we add to this body of literature by emphasizing our findings on the psychological processes that may influence the ability of an individual to engage and benefit in a group cognitive intervention. This information is important for tailoring individual intervention programs and maximizing the benefits of group intervention.

## Methods

This study used a qualitative design with an interpretive description approach. Interpretive description is a methodology used to create a summary of the results that is guided by the researcher's professional view and knowledge.<sup>19</sup> The researchers were occupational therapy practitioners (CB, MC), educators (CB) and students (DF, SF) at the time of the study; an interpretative description approach allowed the researchers to recognize their unique occupational therapy perspective in the development and analysis of the study. Focus groups were selected to enhance the generation of ideas between participants to identify commonalities in their lived experience and group intervention preferences.<sup>20</sup> This study was approved by the affiliated university health research ethics board.

## Sample

Participants were adults with MS who would potentially attend a group cognitive intervention. Inclusion criteria were: 18 years of age or older, self-reported physician-diagnosed MS, minimum one year post-diagnosis, self-reported mild cognitive impairment (defined as trouble with thinking

that makes daily life more difficult according to the individual), ability to participate in a focus group, speak English, and live in the Canadian city where the study took place. Recruitment used three strategies: 1) posters distributed to the local MS chapter, the local MS clinic, and MS society community support workers, 2) recruitment letters sent to randomly selected individuals from a MS research database maintained by the local MS clinic, and 3) snowball sampling. Forty letters were sent from the MS research database to adults living in the region. Potential participants were screened via telephone or e-mail using a screening questionnaire based on the inclusion criteria to determine eligibility. All thirteen participants that were screened were eligible, however, three were unable to attend the focus groups (one had transportation issues, the reason for non-attendance of the remaining two participants is unknown).

## Procedures

Two focus groups were held; each had five participants and lasted approximately 90 min. Participants received the discussion topics in advance via email to help them prepare for the discussion. Two co-investigators with group facilitation training (DF, SF) co-facilitated the groups using a semi-structured focus group guide (see [Table 1](#) for sample questions). Data were gathered by audio recording as well as field notes.

## Data analysis

Data were transcribed verbatim. Transcripts were made anonymous by removing personal identifiers. An inductive approach (interpretive description) was used to analyze transcripts and field notes.<sup>19,21</sup> Consistent with interpretive description, the researchers approached the data without shedding their professional theoretical perspective, but sought to understand the perspectives of the participants, and stayed open to the possibility of the participants disagreeing with the researcher's perspectives. As occupational therapists, the researchers frame their understanding of client experience using the Canadian Model of Occupational Performance and Engagement (CMOP-E).<sup>22</sup> The CMOP-E provides a framework for understanding occupational performance: an individual's ability to engage in the tasks, roles and activities that he or she needs and wants to do in daily life. The ability to engage in occupation is integral to health, and satisfying occupational performance is a result of a good fit between a person's environment (physical, institutional, cultural and social) and personal abilities (physical, cognitive, and affective).

The analysis process occurred in two stages. In the first iteration, coding remained very close to the data resulting in a content-focused analysis. Co-investigators (CB, DF, SF) read the manuscripts through to gain a sense of the whole and then independently coded the data. Codes were compared between researchers to confirm or refute

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