

“A GROUP OF ME’S”: Learning Through Group Process for People Living with Multiple Sclerosis

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Abstract: The purpose of this study was to understand the learning process that took place during a group program for people with fatigue from multiple sclerosis (MS). Group process, acceptance, and self-compassion supported learning. Several types of learning were present. Findings have implications for health educators of people with chronic illness.

Multiple sclerosis (MS) is a chronic, progressive neurological disorder that affects approximately 2.1 million people worldwide (National Multiple Sclerosis Society, 2013). Of the many symptoms of MS, fatigue is one of the most common and most disabling. One well-established approach to address fatigue is fatigue management education provided by an occupational therapist. This method is effective in face-to-face (Mathiowetz, Finlayson, Matuska, Hua Yun, & Ping, 2005), online (Ghahari, Packer, & Passmore, 2010), and teleconference (Finlayson, Preissner, Cho, & Plow, 2011) formats.

Although researchers have discussed why positive changes occur in people with MS who participate in fatigue management education, the focus has been on the group leaders' perceptions of individual group members' progress (Finlayson, Preissner, Stout, & Newman, 2010). Therefore, there was a need for a deeper understanding of the learning process that supported change in fatigue management education from the perspective of people with MS. To address this need, this study explored the learning that took place during a teleconference-delivered, group MS fatigue management program, with attention to how group process facilitated learning and the types of learning that occurred.

Literature Review

Adult learning literature discusses the importance of others in the learning process. Individuals can teach and learn through discussion (Brookfield & Preskill, 1999), use group members as resources for their self-directed learning (Tough, 1967), and engage in discussion that results in a change in worldview (Mezirow, 2000). Other group benefits include feeling less isolated (Liu et al., 2008) and providing motivation to participants (Barlow, Bancroft, & Turner, 2005). Participants can gain hope (Liu et al., 2008) and confidence in their respective abilities to take charge of their health care (Barlow et al., 2005). Practical information and techniques for coping with illness can be exchanged (Kennedy, Schepp, & Rungruangkonkit, 2008).

Much of the literature on the benefits of group process is framed by Yalom's eleven therapeutic group factors (Yalom & Leszcz, 2005). Therapeutic factors represent "different parts of the chance process, actual mechanisms for change, and conditions for change" (MacNair-Semands & Lese, 2000, p. 158). Research concerning therapeutic factors perceived by group

members include cohesiveness in a cancer support group (Magen & Glajchen, 1999), and providing information in a diabetes education group (Ferreira de Oliveira, Munari, Bachion, Santos, & Rosa dos Santos, 2009). Although research exists on group members' perceived benefits while being part of the group such as feeling less isolated (Liu et al., 2008), the research has not specifically addressed the *learning process* that occurs during a teleconference-delivered group-based fatigue management program. Results from this study could inform health educators and augment the literature on learning and chronic illness.

Method

A basic qualitative case study (Yin, 2009) was used with the aim of exploring how and what participants in a group fatigue management program learned from group process and how the group process supported learning. Criterion sampling was used to select participants. Participants had to: (1) be diagnosed with MS by a physician, (2) be age 18 or older, (3) reside in Illinois because the group leader was licensed to practice occupational therapy in the State of Illinois, (4) participate in a program and interviews that were conducted entirely in English, (5) attend at least five of the six sessions of the fatigue management program, (6) have MS fatigue that was severe enough for them to be appropriate for the fatigue management program as judged by a score of four on the *Fatigue Severity Scale* (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989), and (7) score 12 or higher on the *Blessed Orientation, Memory, and Concentration Test* (Katzman et al., 1983) because people with no more than mild cognitive impairment benefit most from an educational program provided in a verbal and teleconference-based format.

Seven respondents participated in the study. Individuals participated in in-depth pre- and post- group interviews conducted by the first author and at least 5 of 6 teleconference group sessions led by an occupational therapist, all of which were recorded and transcribed by the first author. Participants ranged in age from 27 to 64 years with five of the seven participants being 50 years old or older. All participants were White females with the exception of one African American male. All of the participants were unemployed or retired when interviewed.

The qualitative management software, NVivo 9 was used to manage the data. Open and axial coding was used to derive themes (Glaser & Strauss, 1967). Comparisons between transcripts and within transcripts were done to derive themes. Methods of trustworthiness used included peer review, triangulation through multiple methods of data collection, adequate engagement in data collection, an audit trail, and thick, rich description for transferability.

Findings

Several themes about learning to manage fatigue emerged from the data, and were organized by three overarching themes of 1) Group process as learning, 2) Outcomes of the group process and 3) Types of learning. Theme 2 contained the subthemes of changes in fatigue management conceptualization and changes in fatigue management behaviors. Each of these themes is described and discussed below.

Group Process as Learning

The group process supported learning, and interactions were a valuable aspect of the experience. The participants talked about how being in "a group of me's" helped them feel less alone in their illness experience, and how it also supported learning. In addition, they learned through the sharing of information and advice.

A group of me's. The participants learned that other had similar problems and that they were not alone in their experience, which is consistent with Yalom's therapeutic factor of universality (Yalom & Leszcz, 2005) and with Bandura's (1986) social learning theory. Linda talked about how being with "a bunch of me's" was particularly beneficial given that MS fatigue is a hidden disability: "That was so comforting because...almost like a headache, people don't see [fatigue]. They don't understand it, so they don't know it, they don't understand it." Karen had a similar experience: "A big moment for me was when I felt like I was in this with other people."

Knowing that others had similar problems not only made participants feel better -- it supported them in trying new strategies to manage their fatigue. Linda explained how she had received a recommendation from her neurologist to use rest to manage fatigue, but that it did not "click" for her until she was in a "group of me's:"

I do need that rest. And I never did that before. I was given that advice from my neurologist long ago, but it just wasn't me. But now that I've been in the group – a group of me's who agree that the rest is necessary – somehow it clicked.

Group members provided social models which helped them build self-efficacy and feel that if another person with MS could do it, they could do it. For Linda, this encouraged her to try rest as a fatigue management strategy, which further resulted in an experiential learning opportunity.

Sharing information and advice. The participants reported that another beneficial aspect of learning in a group program was the opportunity to gain information, hear suggestions, and receive advice from others. As Sharon explained: "The major thing I learned is how helpful it is to talk to other people about how they're managing this stuff." For example, they learned about the use of equipment such as bath chairs, grab bars, and cooling vests to effectively to manage fatigue. They also learned "the real hands on recipe" -- very practical strategies to address fatigue. Last, respondents valued gaining information that would serve them in the future which was referred to as "cards in my Rolodex." Adults like to learn things to solve problems and these findings demonstrated that reality (Knowles, 1980). The group process aided participants' self-directed learning because they used each other as resources for learning about how to manage MS fatigue (Tough, 1967).

Outcomes of group process

The group process was highly social and experiential. Participants learned new ways of thinking and doing related to managing fatigue. They also learned more about themselves.

Changes in fatigue management conceptualization. As a result of the group interaction, individuals changed the way they thought about fatigue, fatigue management and themselves as persons living with fatigue. For example, James said "There's very little you can do to change some situations, but there are some things you can do to change the way you're *thinking* about it." Some group members had new realizations such as the impact of fatigue on their lives or their behaviors related to fatigue. Other participants became more accepting of fatigue, including Barbara who said: "It's not trying. It's accepting it. Period. The end. I don't try anymore because it takes energy. It does take energy...That's why I'm gonna get one of those little things

that says, ‘It is what it is.’” Several participants engaged in meaning-scheme changes consistent with phases of transformative learning theory (Mezirow, 2000).

Changes in fatigue management behavior. In addition to changes in thinking about fatigue management, the participants changed their behaviors. Prior to the group program, the majority of the participants did not feel that they were managing their fatigue well, and made statements such “I want to do more,” “and “I don’t know, ‘managing’ – I think I’ve adjusted more than managed.” After the six group sessions, however, most participants described positive changes in the ways they were managing their fatigue. These changes included the use of rest, changing standards and priorities, delegating tasks to others, planning the day differently, and modifying activities to manage fatigue. For example, Karen described what she learned about adjusting her standards to conserve energy: “I think the best thing that I learned is standards...choosing better, more realistic goals and standards...I definitely learned that. Because I had no sense of that.”

Types of Learning

The participants engaged in several types of learning, namely social, experiential, informal, and transformational learning. The group setting provided rich opportunities for social learning, especially for social modeling – that is by seeing that other individuals with similar characteristics can be successful (Bandura, 1994). Social modeling was particularly beneficial to learning. For example, Karen heard one participant talk about how she changed her plans with a significant other to manage fatigue and she had this reaction:

And I was just like, ‘oh, if she could figure out a way to do that, boy, I could figure out a way to do, x, y and z.’...That was the moment where it was like, I could stand up for my life too.

The participants also engaged in experiential learning, which is a type of learning that happens as a result of “a direct embodied experience” that engages a person “mentally, physically, and emotionally in the moment” (Merriam, Caffarella, & Baumgartner, 2007, p. 159). Adults can learn through experience however experiential learning also requires reflection and thinking, alone or with others (Beard & Wilson, 2006). In this study, the participants learned through a combination of experience followed by reflection when they returned to the group.

In addition, some informal learning, learning that takes place outside of structured educational programs (Merriam et al., 2007), took place prior to the group sessions -- specifically when the participants were waiting for the sessions to begin. Although these informal discussions initially appeared to be “small talk,” it became apparent that the conversations facilitated learning. For example, conversations about the weather sometimes turned into a discussion about strategies to avoid heat (e.g., use of cooling vests and scarves) to manage MS fatigue.

Finally, examples of transformational learning were evident in the data, specifically changes in meaning schemes which are defined by Mezirow as “sets of immediate, specific beliefs, feelings, attitudes, and value judgments” (Mezirow, 2000, p. 18). One example was from Linda who shifted from being self-critical to being self-compassionate: “They made me forgive my own compromises and I’ve given in to them. I’ve not given up, by no means, but I’ve given in to some things that I can make better through giving in.” Such change is consistent with Mezirow’s assertion that the process of transformation is shared (phase 4). Linda’s quote also demonstrates that she engaged in an exploration of new ways of being (phase 5).

Conclusions and Implications

Group process refers to the interactions of individuals in a group setting (Yalom & Leszcz, 2005). The desired outcomes of group process are typically viewed in terms of developmental outcomes. However, we found that group process facilitated *learning* and that the learning was supported by relationships, comparisons, interactions, and connection to others. Universality helped the participants feel less alone in their illness experience and also facilitated learning. Knowing that others had similar problems supported learning by motivating the participants to try new fatigue management strategies, thus facilitating experiential learning, and also by providing social models that helped the participants build self-efficacy and feel that if another person with MS could do it, they could do it too (Bandura, 1986).

The learning process occurred in three stages. In *Group Process as Learning*, participants learned from their interactions (through social and informal learning) and experiences (through experiential learning). These interactions and experiences influenced their thinking about fatigue and fatigue management, which is the second stage-- *Changes in Fatigue Management Conceptualization*. These changes in conceptualization led the third stage of the model – *Changes in Fatigue Management Behavior*.

Recommendations for health educators include providing clients the experience of managing fatigue in the context of their own everyday lives with opportunities for reflection with others. Second, time should be allowed for individuals to share strategies for fatigue management. Finally, self-efficacy was important to learning. More specifically, two of the four “sources of influence” (Bandura, 1994, p. 72) were found to support learning: social modeling and verbal persuasion. Therefore, more opportunities for participant-to-participant interactions are recommended to potentially enhance opportunities to build self-efficacy.

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