

Enhancing Human Development and Optimizing Health and Well-Being in Persons with Multiple Sclerosis

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This study investigated how persons living with a chronic disease enhance their development and optimize their health and well-being. In-depth interviews were conducted with 13 individuals with multiple sclerosis purposely selected to represent varying demographic and disease characteristics. Cross-interview content analysis was used to examine responses. Achieving goals in physical, social, emotional, cognitive, and spiritual areas was integral to perceptions of optimal health and well-being. Life domains important to achieving and maintaining optimal health and well-being were relationships, participation in everyday experiences of home life, connections to the community, and work. Adaptive processes used to achieve optimal health and well-being reflected those described in the model of selective optimization with compensation (SOC). The findings lend support for the SOC model as one way to conceptualize therapeutic recreation practice and suggest that this framework is useful when investigating questions about how individuals secure optimal health and well-being.

KEY WORDS: *Therapeutic Recreation, Health Enhancement, Selective Optimization with Compensation, Multiple Sclerosis*

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The primary purpose of this study was to explore successful human development and adaptation and its influence on health and well-being from the perspective of individuals with multiple sclerosis. Multiple sclerosis (MS), a chronic, unpredictable neurological disease, presents challenges to enhancing development and promoting lifelong health and well-being. In MS, the myelin sheathing of the nerves is lost in multiple areas, leaving scar tissue. Scarring interferes with electrical impulses to and from the brain producing the various symptoms of MS. The existence and degree of physical and psychosocial symptoms (e.g., motor, sensory, cognitive, and emotional changes/deficits) as either a primary or secondary consequence of MS, may vary from person to person and from time to time in the same person. These symptoms may wax and wane in both frequency and severity (Knight, Devereaux, & Godfrey, 1997; National Multiple Sclerosis Society [NMSS], 2003). Depending on the clinical course of MS (e.g., relapsing-remitting, secondary-progressive, progressive-relapsing, or primary-progressive) episodes of acute worsening of neurologic functioning (relapses, exacerbations) may be followed by partial or complete recovery periods (remissions). Symptoms associated with each of the four clinical courses of the disease might be mild, moderate, or severe (NMSS).

Fatigue, the most common symptom of MS, can exacerbate initial symptoms of MS and lead to secondary losses such as physical deconditioning (Fisk, Pontefract, & Ritvo, 1994). Persons with MS may limit activity to avoid elevated body temperature and to minimize fatigue and related symptoms. Ironically, the result of limiting activity may be greater weakness, fatigue, and risks to physical and psychosocial health (Petajan et al., 1996; Washburn, Zhu, McAuley, Frogley, & Figoni, 2002). When physical deconditioning is coupled with the lack of a predictable pattern of symptoms that is characteristic of MS, a variety of psychosocial symptoms, such as anxiety and helplessness, may also occur. Over time,

steadily progressive functional declines may be observed (Kasser & Stuart, 2001; Stuifbergen & Becker, 2001). These characteristics suggest that persons with MS must demonstrate enhanced adaptivity, a flexibility that enables them to make continuous adaptations to internal and external changes, over their lifespan. Researchers have suggested that individuals with chronic illness, disease, or disability are likely to engage in adaptive responses much earlier in life and to a much greater degree than is expected in typical development (Freund & Baltes, 1998; Freund & Riediger, 2001). Currently, there is no cure for MS and managing its symptoms is an important focus of promoting health and preventing secondary conditions. Many efforts made to manage the symptoms of MS originate with the individuals affected and may include a variety of attempts to cope with and adapt to physical and psychosocial symptoms. Thus, persons with MS provide a unique perspective from which to investigate human development and adaptation as it relates to perceptions of health and well-being.

Working with individuals with MS in therapeutic recreation (TR) practice is particularly challenging as the variable symptoms and progression of this disease as well as the accompanying fatigue and changes in life activities significantly impact the individual's leisure lifestyle (Wenzel, 2000). Therefore, a secondary purpose of the study was to use findings from the study to further develop the Optimizing Lifelong Health and Well-Being through Therapeutic Recreation (OLH-TR) practice model (Wilhite, Keller, & Caldwell, 1999). Primary research questions included: (1) What does optimal health and well-being mean to people living with MS?; (2) How do they achieve and maintain optimal health and well-being?; and (3) Is the selective optimization with compensation model of human development and adaptation a useful way to conceptualize therapeutic recreation practice for persons living with MS?

Concepts of Human Development and Optimal Health and Well-Being

From a life span perspective, human development is a series of interconnected, ongoing, lifelong adaptive processes (Baltes, 1987). These processes are considered both *proactive*—actively selecting and changing particular life contexts and functional domains, and *reactive*—reacting to various personal and environmental changes (Lawton, 1989; Marsiske, Lang, Baltes, & Baltes, 1995). Both proactive and reactive approaches exhibit health enhancing qualities, including the prevention of secondary losses (Hobfoll, 2001; Schulz & Heckhausen, 1996). Human development is also considered nonlinear or multidirectional (Baltes, 1987; Freund & Baltes, 2000). In this paradigm, human development is not merely a process of progression and growth, nor are changes that occur over the life span simply a product of age (Carstensen, 1992). Rather, a more complex interplay exists between individuals' needs and their ability to satisfy these needs. Changes can be both positive (growth) and negative (loss). Human development in this model is approached multidimensionally, capitalizing on individual differences in the level, rate, and direction of change and in the degree of adaptivity or behavioral plasticity (the potential that exists for different forms of behavior or development) (Baltes, 1987; Baltes & Baltes, 1990). Ongoing human development, then, always consists of both gains and losses, within and across life contexts and domains of functioning, shifting toward a less positive balance of gains and losses in late life (Marsiske et al., 1995).

Defined from a Western perspective, successful development across the life span means goal attainment: achieving desired outcomes and avoiding undesired outcomes (Baltes & Carstensen, 1996; Marsiske et al., 1995). These desired outcomes can be defined by objective standards (e.g., range of motion, blood pressure) or subjective standards (e.g.,

life satisfaction, perceptions of health); by different perspectives (e.g., individual, family, health care providers, society); or by different norms (e.g., functional, statistical, optimal) (Baltes, 1997). It is important to note that personal and environmental resources for achieving desired outcomes are constrained and limited at every point of the life span (Freund & Baltes, 2000). In Western culture, resources are defined as valued entities and may include objects (e.g., personal transportation, home furnishings, clothing), personal characteristics (e.g., self-discipline, sense of humor, ability to communicate well), conditions (e.g., free time, social support, financial stability, positively challenging routine), or energy resources (e.g., stamina, endurance, personal health) (Hobfoll, 2001). How individuals manage resources for achieving goals at all ages is a marker of successful development and adaptation (Freund & Riediger, 2001).

Within this developmental framework, optimal health is thus conceived as not merely the absence of biological or mental pathologies, but by aging (living) under development-enhancing or development compromising conditions; maximizing gains and minimizing losses (Baltes & Baltes, 1990; Baltes, 1997). Overall, well-being includes the attainment of an optimal mix of physical, psychological, and social well-being (Steverink, Lindenberg, & Ormel, 1998). The higher the degree of physical, psychological, and social well-being that individuals are able to achieve, the more overall well-being or success they will have (Steverink et al.). Further, Cantor and Sanderson (1999) stated that well-being is enhanced when people are pursuing "their personal goals in ways that are intrinsically valued and autonomously chosen, approached at a feasible level, and facilitated in their daily life context" (p. 230).

Another way to understand successful development and optimal health and well-being is to discuss lack of success and possible negative outcomes of development. Individuals may find it difficult to give up goals that they are highly committed to, that may be

reinforced by their social contexts, and in which substantial resources have been invested. Yet, if the efforts to achieve a goal outweigh the benefits, the most adaptive response might be to give up the goal and select a new, alternative goal (Brandtstadter & Wentura, 1995; Freund & Baltes, 2000; Freund & Riediger, 2001; Schulz & Heckhausen, 1996). Brandtstadter and Renner (1990) found, for example, that inability to let go of unattainable goals was a key feature of reactive depression. Folkman and Stein (1996) reported that the psychological well-being of those providing care for persons with AIDS depended on both relinquishing untenable goals and setting new ones.

Responding adaptively by selecting goals for which resources are still available provides opportunities for gains that may, in turn, provide access to new resources, afford a sense of control, facilitate development in other life domains, and thus provide new opportunities and motivation for experiencing optimal health and well-being (Brandtstadter & Wentura, 1995; Carstensen, 1992; Folkman & Stein, 1996). Hobfoll (2001) referred to these new resources as secondary gains. He contrasted them with secondary losses that occur because of unsuccessful adaptation. Secondary losses not only exacerbate the initial circumstances, but they deplete the resource pool. Freund and Baltes (2000) offered this example of a gymnast who strives to continue performing at previous standards. The gymnast tries to compensate for age-related loss in flexibility by doubling her hours of training. "Overdoing it" eventually leads to irreversible damage to her joints.

A Theoretical Perspective of Human Development

The meta-theoretical model of selective optimization with compensation (SOC), derived from Paul and Margret Baltes' (1990) theory of human adaptation, provided a framework with which to understand successful development across the life span as evidenced by

people living with MS. The model posits that personal and environmental resources are limited at any one specific point in time and that both opportunities and losses arise that require choices about how these resources will be allocated (Baltes & Dickson, 2001). Three interacting elements of this model, selecting, optimizing, and compensating, are described.

Selecting involves choosing roles and activities that match environmental demands with persons' capacities and desired goals/outcomes. Selecting may be elective and not based on losses (e.g., choosing fitness walking over swimming) or loss-based (e.g., choosing swimming because walking is now difficult and fitness benefits may not be readily achieved) (Baltes & Dickson, 2001; Freund & Baltes, 2002). In selecting, individuals choose a limited range of important activities on which to focus energy and attention ensuring that the most valued activities continue at an acceptable level. In this sense, selection does entail costs. Selecting one alternative implies that other alternatives are either restricted or not chosen at all (Freund & Riediger, 2001). Selection, however, is not limited to a continuation of previous goals but can include new or transformed goals (Baltes & Carstensen, 1996). For example, a person may remain committed to physical activity while choosing to participate in a yoga class for the first time rather than continue either fitness walking or swimming. Or an individual who values social interaction may choose to entertain friends at home rather than go out.

Optimizing focuses on ways to maximize personal and environmental resources as a means of achieving goals by drawing on existing reserves and/or augmenting or enriching these reserves (e.g., demonstrating persistence, practicing skills, following nutritional guidelines, taking rests). Optimizing extends beyond setting goals and defining resources available to obtain them. It focuses on using resources in the most effective and efficient manner.

Compensating includes new or alternative

strategies adopted when certain abilities are lost or reduced. These efforts attempt to reduce the impact of functional losses, losses that may be psychological, social, or technical in nature (e.g., listening to books on tape, using a walker or wheelchair, hiring someone to cook meals or perform yard work, using external memory aids, coaching rather than playing a sport).

For practical purposes, selection, optimization, and compensation have been presented as separate processes. In successful human development, however, these processes operate in a coordinated and interrelated fashion and may overlap (Baltes & Baltes, 1990; Freund & Baltes, 2000; Marsiske et al., 1995). Freund and Riediger (2001) proposed that selection provides direction for development and must precede optimization. Through optimization, maximal functioning is achieved that is essential for maintaining health and overall development. Heckhausen and Schulz (1993) argued that optimization serves to regulate selection and compensation so that successful development can occur. As adaptation occurs, access to new resources is facilitated and additional opportunities for selecting are created. Although not specifically identified in the SOC framework, the process of evaluation may be a precursor to SOC as well as a dimension of each element. Researchers have stated that it is the evaluation of circumstances that sets in motion adaptive processes such as SOC (Bouffard & Crocker, 1992; Hobfoll, 2001). Evaluating SOC efforts also provides information regarding how efficiently resources are used and how effectively goals are achieved (Smith & Carlson, 1997).

Methods

The study was conducted in fall 2001 and spring 2002. The Institutional Review Board for the Protection of Human Subjects at the lead researchers' university approved the study. Informed consent was obtained from each participant.

Sample Selection

Thirteen individuals with MS were purposefully selected (Patton, 1990) to participate in in-depth interviews. In purposeful selection, sample members from whom researchers can learn a great deal about the central research questions are selected (Patton). In addition to the primary selection criterion of having MS, maximum variation in personal and contextual characteristics (e.g., age, race/ethnicity, gender, type of MS, socioeconomic status, etc.) was sought. Maximum variation sampling aims at capturing the central categories or themes that cut across a large amount of participant variation (Patton, 1990). Males and individuals of color (e.g., non-northern European ancestry) were also purposefully sought to assure their representation in the study since a diagnosis of MS is less likely in these groups (NMSS, 2003).

Procedures

A team of three trained interviewers conducted two-in-depth interviews with each individual. These interviewers, all of whom had prior interviewing experience, were also trained by the lead author regarding use of the interview protocol (described in the following paragraphs) specific to this study. A face-to-face interview lasting from 60–90 minutes was conducted in a location chosen by the participant (e.g., home, university office, conference room at participant's work). An interview guide was designed to focus discussion on how participants were managing their lives in various domains (e.g., work, leisure, family/friends) while also allowing for the expression of individual perspectives and experiences (Patton, 1987). A key informant, a staff member with the local chapter of the National Multiple Sclerosis Society, participated in the development of the interview guide. Examples of questions from the guide include, "Tell me what optimal health and well-being is for you," "What do you consider to be important activities in your life that contribute to your health and well-being?," "How do you think

you are performing in these activities on a typical day?,” and “What kind of strategies do you use to engage in these activities and experiences?” Clarification and elaboration probes were used to ensure an accurate understanding of participants’ responses. Additionally, as the interviews progressed, the researcher shared insights offered by previous interviewees and invited participants to respond to these comments. The interview was tape recorded and transcribed verbatim. After

analysis of the transcript from the first interview, a follow-up interview was conducted. This telephone interview, lasting from 30–45 minutes (or, in one case, via e-mail), was to ensure that participants’ views were accurately and adequately represented. Discussion focused on a data table that the researcher constructed to summarize the participant’s responses to key study areas (see Figure 1 for an example of a participant’s data table). This table was mailed to the participant in advance

a. Optimal Health & Well-Being	b. Experiences that Contribute	c. Constraints	d. Strategies	e. Process – How?
Listening to my body & adjusting	Reading, watching movies (keeping my mind stimulated)	Heat – hot weather	People – ask for help (“even strangers!”)	Open-mindedness
Doing everything possible to fight MS	Working out, swimming – physical fitness	Fatigue (“often self-induced – not MS fatigue”)	Honesty – “this is a skill” (reaching out)	Trial & error (e.g., finding appropriate meds)
Holistic (emotional, physical, cognitive, spiritual well-being)	Spending time on the computer, Internet (working, being educated, reaching out)	Physical access – “a nuisance”	Scooter, walker (at home), cooling vest	Thinking smarter; being practical
At my best given my situation – individually defined	Good insurance & adequate finances	Cognitive issues (e.g., short-term memory)	Being persistent (“in their face”), assertive	Attitude: <i>carpe diem</i> – “seize the day”
	Taking care of myself – rest, nutrition		Optimizing – drive thru, delivery, time of day (meds on or off)	Education – learning about MS & myself
	Family & friends – “I want to be where my family & friends are.”		Adjusting goals & priorities	Acceptance
	Helping others – peer supporter, advocate		Outsourcing – cooking, cleaning, etc.	

- a. Participant’s description of optimal health and well-being**
- b. Experiences or activities that contribute to optimal health and well-being**
- c. Experiences or situations that detract from optimal health and well-being**
- d. Strategies used to achieve or maintain optimal health and well-being**
- e. Processes that led to the development/discovery of these strategies**

FIGURE 1. SAMPLE PARTICIPANT’S SUMMARY PROFILE.

of the interview. The participant was asked to review the table and consider the information in each area. About one week later, the researcher sought clarification, confirmation, or expansion of the areas so that it was certain that appropriate interpretations had been made. This procedure helped to ensure trustworthiness of the data by verifying the meaningfulness and accuracy of the identified areas or categories and the assignment of data in the categories.

Data Analysis

Transcripts from the initial interview were independently reviewed by each of three researchers at the lead university. Cross-interview content analysis (Patton, 1990; Weber, 1985) was used to examine responses in the primary categories of (a) perceptions of optimal health and well-being, (b) experiences or activities that contribute to and/or detract from (i.e., constraints) optimal health and well-being, (c) strategies for optimizing health and well-being, and (d) processes that led to the discovery and development of these strategies. In cross-interview analysis (also referred to as cross-case analysis by Patton, 1990) common questions and/or topics from the interview guide provide an a priori descriptive analytical framework for analysis; responses from different participants are grouped according to these categories.

The goal of data analysis was to establish a common understanding of the identified categories through extensive discussion of participants' responses. Each of the three researchers individually identified quotes or paraphrased quotes and grouped them according to the a priori categories described in the previous paragraph. During this process, the researchers read and reread interview transcripts, working back and forth between the interview data and the primary categories. After independent review, data and their groupings were consensually validated among the three investigators during group meetings. Credibility of data was established further by

discussing preliminary findings with the key informant. This individual helped the researchers clarify and confirm data categorization. Although infrequent, when inconsistencies and differences arose over groupings, discussion ensued until consensus was reached. Disagreements were minor, generally related to data fitting into more than one category, and all differences were easily resolved.

Researchers then constructed individual data tables that summarized responses in these key areas from each participant. As presented in the previous section, researchers used this table to focus discussion in follow-up interviews. The researchers sought clarification, confirmation, or expansion of key areas to ensure that accurate interpretations had been made. After reviewing their data tables and participating in the follow-up interview, all participants confirmed that the researchers had accurately understood and reflected their responses. Revisions, where needed, involved incorporating additional data that helped to clarify and/or expand a key area. For example, "friends and family support" were listed on one participant's data table under the category of "experiences or activities that contribute to and/or detract from optimal health and well-being." When reviewing the table, the participant stated that he considered the individuals who worked with him at the hospital to be part of his "family."

Results

Sample

The sample was comprised of three men and ten women ($N = 13$) ranging in age from 27–70 and living in the community. Basic demographic information about the sample is presented in Table 1. Ten of the respondents were Caucasian, two were African American, and one was Hispanic American. Ten of the participants were married, two participants were single, and one participant was divorced. The participants had been diagnosed with MS from 2 to 27 years. Each of the four clinical courses of

Table 1.
Demographic Characteristics

Name*	Sex	Age	Diagnosis	Type	Ethnicity	Marital	Employment	Financial
Leta	F	27	2000	Relapsing-Remitting	African Am	Single	Full-time	Fair
John	M	27	1999	Secondary-Progressive	Caucasian	Divorced	Unemployed	Fair
Cara	F	36	1990	Relapsing-Remitting	Caucasian	Married	Unemployed	Fair
Lisa	F	36	1984	Secondary-Progressive	Caucasian	Married	Unemployed	Fair
Gina	F	36	1993	Relapsing-Remitting	Caucasian	Married	Full-time	Good
Rose	F	42	1980	Secondary-Progressive	Hispanic	Married	Unemployed	Fair
Beth	F	45	1994	Relapsing-Remitting	Caucasian	Married	Full-time	Excellent
Nat	F	45	1993	Primary-Progressive	African Am	Married	Unemployed	Fair
Thom	M	47	1975	Relapsing-Remitting	Caucasian	Single	Full-time	Excellent
Glen	M	49	1997	Progressive-Relapsing	Caucasian	Married	Unemployed	Fair
Ruth	F	54	1985	Primary-Progressive	Caucasian	Married	Unemployed	Fair
Karen	F	55	1976	Primary-Progressive	Caucasian	Married	Unemployed	Excellent
Mae	F	70	1986	Primary-Progressive	Caucasian	Married	Unemployed	Poor

* Pseudonym

MS, relapsing-remitting, secondary-progressive, progressive-relapsing, and primary-progressive was observed in the sample. Eight of the participants were currently unemployed due to their MS and one participant was unemployed prior to the onset of MS. Four participants were employed full-time. Most of the respondents perceived their financial resources to be fair to good although the oldest participant stated "poor."

In the following paragraphs, the results of cross-interview content analysis are presented. Results are organized according to the primary categories of (a) perceptions of optimal health and well-being, (b) experiences or activities that contribute to and/or detract from optimal health and well-being, (c) strategies for optimizing health and well-being, and (d) processes that led to the discovery and development of these strategies.

Perceptions of Optimal Health and Well-Being

Perceptions of optimal health and well-being were holistic and included physical, social, emotional, cognitive, and spiritual well-being. These perceptions were both self-oriented (e.g., "doing what I want to do," "enjoying life") and other-oriented (e.g., "being involved in my children's activities," "inspiring others"). Life domains that appeared important to achieving and maintaining optimal health and well-being included relationships, participation in the everyday experiences of home life, connections to the community (e.g., attending church, social outings), and work. Within these domains, participants discussed a variety of experiences and activities that afforded personal meaning ("I love to volunteer"), health benefits ("swimming is great"), and self-determination ("to just do it myself"). Additionally, the majority of participants considered financial security a critical aspect of optimal health and well-being.

The process of first identifying, then working toward, and finally achieving goals was

integral to participants' descriptions of optimal health and well-being. Participants demonstrated a high degree of self-acceptance when defining goals and measuring progress. John¹ explained:

Back then [before MS] optimal health, optimal living meant I reached someone else's goal. And now, for me the most satisfaction, the largest reward is I did something to satisfy myself. Ok, I lived up to this standard. How can I do it better next time? . . . Setting goals is important. The best way to guarantee failure is to never try. If I can't meet my goals, it is important that I at least try.

Optimal health and well-being did not imply that participants were living symptom-free. In the following example, Beth recognizes some losses in her physical self (i.e., sensory and motor deficits), while identifying social, emotional, and cognitive aspects of her life that she equates with optimal health. Beth stated:

Well, maximum optimal [health] would mean I don't have tingles and I can walk as far as I want to walk. [However,] the fact that I can go to work, I can go to school, I can go out and drink beer on a Tuesday or Friday night. I can sit out on our patio with my husband and have friends over. That is the picture of optimal health.

The comments of Beth and other participants include an important attitudinal component that was also identified as part of optimal health and well-being. When asked, "What is optimal health and well-being to you?" Mae's response demonstrates how a positive outlook is vital to her perception.

¹ Pseudonyms are used throughout the manuscript.

Getting up and feeling good. I try to be positive about it [MS] and try to get out of the house; that's a big thing. I like to be with friends and go to the exercise program. I don't know; just have a pretty good outlook on life. . . . You have to fight to not have the "poor me" attitude. That is the biggest one that you can have with MS. You have to say, "Oh, I am doing that [feeling sorry for myself]. I have to stop it and do something else."

For some participants, staying positive included "doing everything possible to fight MS." Lisa explained:

I have come to terms with my MS and accepted it. But I am a fighter. Resistance is not denial. . . . And I don't care how minute it may be. You have got to do something to give yourself empowerment. To feel that you are fighting back, as little as it may be.

Other participants also spoke of fighting back, yet emphasized in hindsight the importance of "recognizing when to back off and get a little rest." John recounted:

I think that is one of the reasons that I fell so far into a coma. Physically I pushed myself. Mentally I pushed myself. I was not going to accept MS no matter how bad it hurt.

Rose, who had been using a wheelchair for about five years, shared that she "didn't want to surrender" to a walker or wheelchair because she felt like she was "still mostly whole" if she continued to use a cane. She stated, "I guess it was kind of a denial." In addition, Rose perceived using a wheelchair as an inconvenience for both her and her husband: "This thing [wheelchair] is hard to get around." Upon retrospection, however, Rose stated:

I never could use a walker because I toughed it out for too long with a cane. . . . If I were to see someone using a cane like that I would say give it up. Use a walker or a wheelchair because using a cane like that makes your life tougher than it needs to be.

Activities Contributing to Optimal Health and Well-Being

Participants identified a variety of experiences and activities that contributed to their optimal health and well-being. These data, discussed in the following sections, reflected the life domains of (a) relationships, (b) everyday experiences of home life, (c) connections to the community, and (d) work.

Relationships. Relationships were an essential aspect of optimal health and well-being. In some instances, these relationships were faith-based. Lisa felt that her emotional and spiritual well-being were strongly connected and provided a focus for her goals. She explained:

Having such strong faith, I know I am not in this alone. If I didn't have such a strong faith I am sure there would be a lot of anger. I would ask, "Why God, why me?" I ask that in a good way, not a bad one. Like, ok, you have chosen me, give me the direction. And I have the direction.

Mae shared:

Well, my religion, believing in God, has helped me [cope with changes in health] a lot. And people who come around from Sunday school and church. They help me a whole lot.

In addition to spiritual relationships, participants also perceived their relationships with friends and family as necessary for optimal health and well-being. As John stated, "Friendships are important—I have to have

social contact, HAVE to have” [emphasis added]. Gina shared that much of her life revolved around family and friends and that she derived great support and enjoyment from these relationships and activities. Lisa stated that “having family and friends over is exciting for me.” She observed, “I want to be where my family and friends are.” Glen, a veteran who participated in many activities through the Veterans Affairs (VA) Hospital, provided this illustration:

The relationships with my friends at the hospital, my VA family, help keep me going. . . . Sometimes it is hard for me to explain MS. . . . But I have camaraderie with my friends at the VA. We’re all in that fraternity.

For some, phone calls or the Internet facilitated connections to others. Karen talked about having “. . . a network of people that I call who are handicapped” and how she enjoyed, “. . . e-mailing people back and forth. It is fun.”

Participation in everyday experiences of home life. Participation in the everyday experiences of home life, often with family members or friends, was also important to participants’ optimal health and well-being. Mae discussed feeling good when she was able to get in the kitchen and cook:

It [cooking] is a joint effort with my husband. He does the chopping to help me and I have to just holler at him when I need some help.

Ruth talked about how she got “grumpy” if bad weather prevented her from going outside in her wheelchair to talk to her neighbors or check on her garden.

In some cases, these everyday activities were infused with positive meanings and, in that light, were considered leisure by the participants. Thom stated that he “loved yard work” both because of the physicality involved in taking care of the yard and the aesthetic appreciation gained by observing the

beauty of the yard. In another example, Cara’s grandmother, who lives in a nearby city,

. . . is always coming by and checking on me and I check on her. We kind of watch out for one another, hang out. We have a lot of the same interests. Love to do arts and crafts (. . .) love to bake and cook.

Lisa spoke of how she enjoyed the simplicity of watching the world around her:

It brings me joy, looking at the flowers and saying, man, that tree has three more blooms on it. I notice that stuff on a daily basis. Like the dove. I was so glad she nested there. The babies were born and we were there with binoculars. So now, we see the babies and Gracie and Hercules [momma and daddy dove] all over the lawn. I notice that now. I never would have noticed that before [MS].

Glen described how he maintained written records (e.g., journals, calendars) of his day-to-day activities to help him with memory loss. These records also served as a source of enjoyment: “Looking over my journals is also an enjoyable activity for me and my wife. It is a type of legacy of my life. Our life.”

Connections to the community. Identified as important to their optimal health and well-being, participants were also involved with activities outside the home. Examples included movies, dinner, concerts, children’s activities, shopping, game nights with neighbors, traveling, MS support group meetings, and neighborhood association meetings. Several community activities were physical in nature such as working out, walking, swimming, horseback riding, wheelchair sports, and bowling. Leta talked about walking around her neighborhood and swimming at the pool:

I do a lot of walking and I love to go swimming. Swimming is great. There is

no impact and it keeps you cool at the same time.

Rose described a special skiing vacation this way:

This summer this couple we [Rose and husband] met at horseback riding—he is a paraplegic and she is a nurse practitioner—they talked us into going to Santa Fe to go skiing at Christmas time. They have an adaptive ski program and we did that and I had a lot of fun.

Other community activities involved aspects of caring for others. Lisa announced, “Being a peer supporter/advocate is why I’m on the planet.” Ruth talked about sewing bags that nursing home residents could hang on their wheelchair. She explained:

We made these pouches and eyeglass cases and the church filled them with powder and stuff. We took them to the nursing home as a Christmas present to everyone. I enjoy going to the nursing home.

Work. Regardless of employment status, several participants identified work as important to their optimal health and well-being. Work was valued for the intellectual stimulation and challenge it provided, the opportunity to enjoy positive coworker interactions, the feelings of productivity, and the financial rewards. Gina, for example, felt that staying busy through meaningful work contributed to her health and well-being. Gina shared, “I enjoy it [work] so much.” Lisa was proud of her success in a challenging sales job and also appreciated the financial benefits it provided. Although no longer able to perform in her sales job, she enjoyed working from home as an advocate for a well-known MS drug, and as a peer supporter. Still, she missed working outside the home and stated, “If I could go into the office every day, I would be working. I am not lazy, but that [going into the office every

day] took its toll on me.” Thom stated that financial security and feeling supported at work were two of the most important aspects of his optimal health and well-being. Thom, who was single, stated that financially he could “retire today” at age 47; however, he expected he would “probably work until I am about 60.” Glen, who was not working due to MS, missed the financial security, relationships with coworkers, and feelings of productivity that work provided. Without work, Glen struggled to avoid feeling bored: “I was thinking instead of doing nothing, what can I do that is something?” Beth described the relationship of work to her optimal health and well-being in this way:

I am the primary income earner in our family. So the lifestyle that we live is on me. So for me to be able to keep my body manageable to be able to do my job is first priority.

Strategies for Optimizing Health and Well-Being

Participants were using a variety of adaptive strategies to enhance their development and optimize their health and well-being in the various life domains. An examination of these strategies revealed that they could be organized to reflect the adaptive processes described in the SOC model.

Selecting. Participants focused their personal and environmental resources on those life domains and activities that they felt were most important to their optimal health and well-being. In these domains and activities, participants chose, developed, and committed themselves to goals. For example, Mae talked about her and her husband’s goal to travel more during the upcoming year:

We belong to a group, Prime Timers, in our church and do some activities. I am hoping that this year since I am better that we can take some of the little trips with them. I have not been able to do

that in the past. I am hoping to go to Oklahoma City.

John related the importance of working toward goals in this way:

You cannot imagine what a release it is (. . .) to have a goal and accomplish it, to feel better about yourself—such a good feeling. When you have that feeling, you want to have it again. It [accomplishing goals] is something that is motivating.

Ruth's goals included "staying involved in life." She described how she enjoyed participating in activities that "got her out of the house," such as attending church, going to MS support group meetings, shopping, and volunteering at the nursing home. Lisa, a self-described "workout junkie," was very committed to her in-home exercise routine:

I work out six days a week on the Total Gym. I get on that machine for 20 minutes and I am dead. It takes everything I have to get back down the hall. But I can't get enough of it. If I can't work out, I am in a really bad mood. A really, really bad mood. In fact, I won't go on vacation for more than five days because I can't work out. I am out of my routine.

Selecting was sometimes loss-based or *re-active* and involved adopting new goals and/or activities. Lisa, highlighted in the above example, started working out at home after going to the pool to swim became too physically demanding. She stated, "As MS marches on, your goals have to change." Along with some losses, however, she identified gains. "I never took time to read. Now I slow down and read." Nat used to go to church two days a week, but now, for health reasons, limits attendance to one day a week. As an alternative, Nat watches religious programs on television or listens to religious tapes. Cara felt time spent with her

children was a priority. In putting her children's activities and needs first, she adjusted her standards in other areas of her life, like household duties:

I have learned that it does not have to be perfect. That is one of the biggest things—to know that my kids are happy and healthy. That is the main priority. A clean house doesn't need to be priority.

Cara emphasized, however, that sometimes selecting one desired activity might mean giving up another. She spoke about her decision to miss her husband's company picnic in order to have enough energy to attend a dance recital with a friend. In evaluating this choice, Cara explained, "It weighs out."

Beth chose to keep a previous appointment rather than participate in an activity that she believed would compromise her health:

My girlfriend called and asked me to go to the motor speedway and I said no. I legitimately had something else to do, but I thought, she doesn't know what she is getting into. I can't walk. I have my handicapped sticker and we could park really close, but I can't do that. The heat. . . I wouldn't put myself into that situation.

Optimizing. Strategies of "knowing my body," resting, organizing, "educating myself," and maximizing ("not wasting") energy were routinely used to optimize engagement in chosen life domains and activities and to help manage progressive losses. Participants stressed knowing their physical capabilities. They talked about the importance of practicing good nutrition, exercising, getting enough sleep, taking their medications, and learning everything they could about MS. They planned, determining the best time of day to perform certain tasks, and tried to stay organized so that they could minimize stress and maximize rest. Some optimizing strategies, such as minimizing heat liability and manag-

ing fatigue, were unique to MS. The following examples illustrate many of these optimizing strategies.

Lisa explained that she does her:

...chores in the morning, like dry cleaners, bank, that stuff. Before it gets hot. Sometimes I go to the grocery store. If I do, it is for an item or two. If it is big grocery shopping and I don't have them delivered, [my husband] and I will both go. He is such a help to me.

Cara provided several examples of how she optimized engagement in selected activities:

If I know I am going to be standing, I try to alter it so I can sit down. For instance folding the laundry. Instead of standing at the dryer, I take it and put it on the love seat and I can sit down. I let the kids run errands. I try to do my shopping during the week. . . Going during the week with less people, it helps. The Internet is great. You can cut down on some of your running with that. I have done Grocery Works and online shopping. It is wonderful to have.

Participants also spoke of the value of persistence, which sometimes included trial and error, in optimizing participation in chosen activities. John stated:

This way isn't working for me, but this way might. Give that a try. I'm always trying to come up with new stuff.

Persistence was also demonstrated in Karen's simple yet determined declaration: "If it is important to me, I figure out a way to do it."

Compensating. When participants experienced losses in personal or environmental resources, they used a variety of compensatory strategies that included asking for help as needed, delegating tasks when necessary, using assistive devices, acquiring new skills, and

substituting one activity for another. Once again, participants might readjust goals or life roles when deemed appropriate, or used sheer persistence and determination to resist changing goals/roles. Researchers observed that SOC processes sometimes overlapped making it more difficult to distinguish them for purposes of analysis. For example, persistence, which could include increasing the amount of effort, energy, and/or time allocated, may be both a means to enhance goal achievement (optimizing) and a resource for counteracting loss or decline (compensating). Thus, some strategies are described as both optimizing and compensating.

A variety of compensations were used to maintain mobility and to tend to household and personal tasks. In-home mobility was enhanced through the strategic placement and use of furniture (e.g., bringing a stool into the kitchen, placing a box springs and mattress on the floor), use of vinyl flooring rather than carpet, installation of grab bars in bathrooms, use of a bath tub chair, and addition of wheelchair ramps. Participants reported using canes, crutches, walkers, wheelchairs, or even the arm of another person to assist further with mobility. Substitutions such as sitting instead of standing, typing instead of writing, or using public transportation instead of driving were also reported. Once again, some compensation strategies were specific to living with MS, such as the use of a cooling vest; the use of calendars, lists, and journals to aid with memory; or allotting more time to complete desire tasks.

Compensatory efforts were also evident in other life domains and activities. Beth talked about how compensatory efforts enhanced leisure participation and afforded a sense of control:

We were doing all of the Orlando stuff that you do. My friends were like, 'we can't go as fast as we used to because you have to rest.' The second day one of my friends said, 'we'll just get a wheelchair. You can't walk, we'll just push

you around.’ And it really worked out ok. That was a subconscious thing that if someone wants to offer me a wheelchair, I will take. Actually, I will take a scooter next time so I can be in control.

Likewise, Cara stated that she would simply “move a little slower” or “have the kids be my legs if I am feeling bad” to assert control and perform adequately in activities involving her children. Karen took pride in her ability to “find ways to get out, ways to do things.” She described how she handled her groceries this way:

When I go I ask for a banana box to put my things in. I have a luggage carrier and lots of bungee cords and I bring all my things home myself and get them in the house and put them up.

This final example summarizes the interplay of SOC processes and demonstrates how evaluating—weighing costs and benefits of engagement—can be an important part of these processes. When talking about activities that contributed to her health and well-being, Mae explained:

I am a member of the Tapes for the Blind. So, I use those and listen to those every day. My eyesight fluctuates. I don’t have enough eyesight to read and if I read I have to read large print and I still have to restrict how much I read and I like to do my sewing more than read [i.e., selecting]. So, I use those tapes [i.e., compensating]. I lay down in the afternoon to listen and sometimes take a little nap. It is relaxing. If I have tension, I can go in there and close the door and turn one on and relax [i.e., optimizing].

Discovering and Developing Strategies

Participants were able to describe how they discovered and developed the adaptive strate-

gies discussed in the previous section. As illustrated in earlier statements made by Lisa, John, Karen, and others, discovering and developing strategies was sometimes the result of sheer will or determination and exhibited through simple trial and error. In other instances, participants described a more deliberate process aided through education (e.g., learning about MS through reading, researching a topic on the Internet, going to seminars, listening to my body), support and encouragement (from family members, friends, health care providers), and exploration of options. Participants also often learned about various strategies through observation. Rose stated, “Observing others with MS or another disability is the biggest light bulb.” John felt that he had a large network of friends because of his affiliation with the VA Hospital. He talked about how he turned to these friends and learned from them—watching how they accomplished tasks, asking questions, and receiving encouragement. He described one such encounter:

I asked him, have you ever tried this and got so close to working but never got it? And then he says, well yeah, I just did this. Oh wow. And you know (. . .) it worked.

The process of discovering and using an adaptive strategy could be a collaborative as well as an individualistic effort. The input, expectations, needs, and assistance of others including family, friends, and health care providers, were often sought and considered as participants contemplated and implemented adaptive efforts. Karen explained that she discovered some desirable strategies through cooperative problem-solving. She told of one instance in which she approached her son for ideas:

I said to my son (. . .) I can’t figure out what to do to get stuff when I am in my bed. And he took my cane and put it between my mattress and box springs

and I hang my Bible and books on the cane. Simple.

When Ruth was asked how she made choices about activity participation, she stated, "It depends on what Janice [paid caregiver] wants to do or what my husband wants to do." Ruth added, however, that she is not afraid to consider other participation options, even without the involvement of her caregiver or husband. She expressed her determination in this way: "I have not given up. There is a way, there is always a way." Gina talked about how her husband challenged her through "positive nudging." She stated:

Sometimes if I say something about I am hurting, he will say are you really or are you just putting it off on MS? And it will make me think. And if it is MS, he will just give me the room, but he doesn't want me to just give up or get depressed over the disease. He is very supportive and he challenges me.

Leta spoke about the importance of collaborating with her neurologist. She stated, "He will call me and check on how I am doing. He also scolds me when I do something I shouldn't."

Discussion and Implications

Defining and Achieving Optimal Health and Well-Being

In our previous research with the OLH-TR model (Wilhite et al., 1999), we stressed the need to understand further how persons with disabilities might define concepts such as health and well-being. In the present study, participants were able to easily explain what optimal health and well-being meant to them. Their perceptions included the specification of relevant goals sought in meaningful life domains and activities. They accomplished these goals using personally appropriate and available means. Participants modified these goals, or the means to achieve them, as necessary.

Optimal health and well-being were perceived holistically and achieved in valued life domains and activities such as family and friends, daily life experiences, and leisure. A few participants perceived that they did not have optimal health (e.g., absence of MS, being able to walk), but that they had achieved optimal well-being. As Karen stated, "I am doing the best I can and seeing positive results."

Once participants identified goals and sought to obtain them, a process of monitoring progress (or lack thereof) was employed. Participants considered feedback from their behaviors, including feedback offered by others. Participants considered whether they were obtaining their desired outcomes and at what cost to personal or environmental resources. In turn, a type of feedback loop was observed in which evaluative information served as an antecedent for changes. Changes might be made to the content or structure of goals (i.e., selecting) and/or the means by which the goals were achieved (i.e., optimizing and/or compensating).

Participants in the study were observed to be striving for optimal health and well-being at a personal level. Yet, their behaviors were often socially constructed as spouses, children, friends, and health care providers participated in the process of *selecting* mutually relevant goals (e.g., choosing to travel with a spouse), *optimizing* the means to achieve goals (e.g., letting the children run certain errands), and collaborating on *compensatory* strategies and means when necessary (e.g., recommending the use of a cooling vest). Understanding shared or collective SOC processes has been a focus of recent efforts to develop further the model of SOC (Baltes & Carstensen, 1999; Freund & Baltes, 2000). Collective SOC processes observed in this study were pragmatic as participants realized that their successes depended, in part, on the actions of others. An example was when Beth's friends indicated, "You can't walk, we'll just push you around." The approach was also preferred, however, as participants' goals often revolved around sup-

porting and encouraging the goals of family members and friends (e.g., viewing children as priority, taking care of household tasks, meeting friends for dinner). A potential downside of collective SOC was observed when personal and collective goals were different. Rose talked about how her participation in a community activity would be limited by lack of support from her husband. She stated, "I would find it interesting, but he [husband] doesn't."

The findings also increase our understanding of successful development. Sometimes, gains could prove too costly as in the example by Rose who perceived that her goal to continue walking, rather than use a wheelchair, actually made her life harder—both physically (e.g., fatigue) and emotionally (e.g., denial). Her resistance compromised her physical resource pool. She described how she was not able to use a walker as an interim step to using a wheelchair, something that she would have liked to do. Her emotional resources were taxed as she struggled to accept her physical limitations and avoid "feeling like a burden" to others. At times, gains were derived from losses that participants attributed to MS by "forcing" them to define life priorities, reach out to and connect with others, initiate a new goal or activity, or appreciate activities and experiences more fully. Mohr et al. (1999) referred to this occurrence as "benefit-finding" and suggested it included a deepening of relationships, an enhanced appreciation of life, and an increase in spiritual interests. Lisa's comments provided one such example when she explained that before MS she never took time to read. "Now I slow down and read."

Beliefs that losses are inherently "bad" and gains are inherently "good" are influenced by culturally-biased assumptions (Baltes & Carstensen, 1996; Freund & Baltes, 2002; Marsiske et al., 1995). Likewise, decisions about whether to resist or adapt may be culturally influenced (Lazarus, 1993). Recognizing the differences in people and their environments, Baltes and Baltes (1990) suggested individual and societal flexibility was impor-

tant in defining and obtaining success. Goals are selected in accordance with changing personal, biological, and societal needs (Freund & Baltes, 2002). Means for optimizing or compensating must be compatible with personal and social values and supported through societal opportunity structures (Freund & Baltes, 2002).

Baltes (1997) considered whether the SOC model itself carried a cultural bias. He recognized that the terms selection, optimization, and compensation, because they are sometimes associated with notions of economic productivity, might suggest a bias toward industrialized Westernized societies. Baltes concluded, however, that a unique strength of the SOC model was that it was at once relative and universal. The relativity of SOC is found when considering personal and environmental contexts. As observed in this study, definitions of optimal health and well-being, criteria used to define successful development, and resources used to achieve successful development reflect the variety of individuals and their sociocultural contexts (Baltes & Baltes, 1990). "Thus, SOC, depending on sociocultural context, individual resources, and personal preferences, can be implemented in very different ways and by different means" (Baltes, 1997, p. 372). The generalizability of the theory lies in the argument that human development in and of itself requires some application of SOC processes to maintain and/or advance adequate levels of functioning (Baltes & Baltes; Marsiske et al., 1995).

Implications for Therapeutic Recreation Practice and Research

As individuals living with chronic illness and disability respond again and again to changing situations, health status, and environments, TR professionals are challenged to keep their services relevant and meaningful in relation to how these individuals and their loved ones are actually living their lives. The study findings lend support for the SOC model as one way to address this challenge. As such,

the findings are instructive in the authors' efforts to continue the development of the OLH-TR practice model. Based on the study findings, the OLH-TR model's framework of selecting, optimizing, compensating, and evaluating may guide therapeutic recreation specialists (TRSs), people with disabilities, and important others as they collaborate to optimize health and well-being over the life course. Within the OLH-TR model, both education and facilitation orientations may enhance personal and/or environmental resources. On a personal level, *educational* efforts might mean helping someone acquire awareness and understanding of various recreation options for optimizing health and well-being. Participants in this study were knowledgeable about the importance of engaging in recreation and leisure activities and experiences. TRSs should not assume, however, that all individuals with disabilities will be as able to appreciate and/or articulate the benefits of such participation. Even when participants understand the value of recreation and leisure engagement, they may benefit from the assistance of a TRS who helps them develop feasible goals, participates in the *selection* of appropriate functional domains and target activities, and educates them about ways to *optimize* their participation. TRSs may also help individuals with disabilities and their loved ones *compensate* for changing personal resources by acquiring new skills, adapting activities, or substituting activities as appropriate. On an environmental level, TRSs may direct *facilitation* efforts toward ensuring that people have physical and programmatic access to recreation opportunities and that their participation is welcomed and supported. Once again, TRSs must not assume that all individuals will have the same access to personal and environmental resources that was demonstrated by the study participants.

SOC processes appeared to be especially well-suited for addressing *education* in the areas of prevention and health promotion. Rather than simply waiting for stress or loss to occur, study participants positioned them-

selves in situations and circumstances that were advantageous by anticipating obstacles and preparing for them. Examples offered by Cara, Beth, Leta, Mae, and others demonstrated how decisions were made in an attempt to circumvent negative or stressful situations before they occurred. For example, the friendships that Mae, who had just turned 70 years old, was able to cultivate early in her life through work and leisure contexts were essential to her present health and well-being. Leta, who talked about the importance of exercise in maintaining her health and well-being, determined that riding bikes with her children was something she could do "with no pressure." She stated, "If I got on a treadmill, I would be hurting; but the bike I can do." As TRSs intervene at one point in time to help individuals augment and enrich their leisure-related reserve capacities and resources, they may also help individuals to maintain optimal health and well-being over the life course. TRSs can use the examples offered by these study participants to help those participants who are unable or unwilling to actively and selectively engage in healthy leisure behaviors and activities.

As described in an earlier section, some use of the SOC processes by participants was deliberate while other use was automatic. It is difficult to alter automatic or subconscious processes, even if these processes are creating development-compromising conditions (Freund & Baltes, 2000). Affording evaluation a place in the OLH-TR model may help TRSs to facilitate educational efforts by making the process of self-monitoring, or monitoring by others (e.g., family, TRS), more visible and the positive application of SOC processes more likely. Through *evaluating*, TRSs can help individuals with disabilities make healthy lifestyle choices by encouraging them to identify and consider both the benefits and costs of certain behaviors and activities.

Finally, TRSs' may apply the findings of the study to their practice by tailoring the SOC processes to the specific personal and environmental contexts of individuals. In this study,

personal, social, and cultural variations were particularly evident in collaborative approaches to how decisions/choices were made and implemented. Education and facilitation efforts of TRSs can be directed toward achieving a shared understanding and appreciation of collective optimal health and well-being. When resources are more restricted, individuals and significant others will need to consider the interplay of independence, dependence, and interdependence. SOC strategies would not only be customized to an individual's opportunities and limits, but to a family's or community's opportunities and limits (Baltes & Carstensen, 1999). Accordingly, TRSs could apply collective SOC strategies on a micro-level, as with a couple; on a meso-level, as with a family; or on a macro-level, as with a health or human service organization (Baltes & Carstensen).

From a research perspective, the findings suggest that the SOC framework is a useful way to investigate questions about how individuals effectively secure and maintain optimal health and well-being in various life domains. Thus, the results of this study suggest that future research is warranted. Some of the challenges and limitations of this study provide direction for future research. For example, it was difficult to find participants of color and men with MS, as the disease is predominant in Caucasian women (NMSS, 2003). Samples that include greater diversity in regard to race, cultural background, gender, and socioeconomic status should be sought in the future in order to determine how experiences using SOC processes are similar or different. Individuals who have not been as successful in their attempts to achieve optimal health and well-being, as were the participants in the present study, should also be sought.

Empirical research should be directed toward determining whether individuals with disabilities who report using developmental strategies consistent with the SOC model also report higher levels of functioning in subjective and objective psychosocial and physical measures. Additionally, future research should

focus on whether the use of SOC processes varies by personal characteristics such as age, race, cultural background, gender, socio-economic status, length of illness, and perceived intrusiveness of impairment. Conducting these studies with probability sampling will enable generalizability.

In summary, our purpose has been to explore how individuals living with a chronic disease such as MS enhance their development and optimize their health and well-being. Persons with MS described optimal health and well-being from both a person-centered and a contextual viewpoint and used a variety of strategies to achieve success in valued life domains and activities. While not living "symptom-free," participants' perceptions of optimal health and well-being were similar to Hales' (1997) view of health as "the process of discovering, using, and protecting all the resources within our bodies, minds, spirits, families, communities, and environment" (p. 16). The various strategies used by participants reflected the adaptive processes described in the SOC model. Thus, the SOC model may provide a structure for continued investigation of the range of strategies and behaviors people use to achieve optimal health and well-being. Such evidence may lead to the development or refinement of TR practice approaches that help individuals with chronic disease or disability become active agents in securing and maintaining quality of life.

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