Quality of Life and Symptom Severity for Individuals With Chronic Fatigue Syndrome: Findings From a Randomized Clinical Trial

Renée R. Taylor

KEY WORDS
. fatigue intervention
. participatory action research
. rehabilitation program

OBJECTIVE. Chronic fatigue syndrome is a profoundly disabling condition characterized by severe, unrelenting fatigue and a number of other physical and cognitive symptoms. Currently, there is no cure or widely accepted treatment for chronic fatigue syndrome. and few rehabilitation programs exist to address quality of life issues in chronic fatigue syndrome. In the present randomized clinical trial. the effects of an integrative. consumer-driven rehabilitation program on quality of life and symptom severity for individuals with chronic fatigue syndrome were examined.

METHOD. Forty-seven participants were randomly assigned to either an immediate program group *(n*= 23) or a delayed program control group *(n*= 24) and assessed with the Chronic Fatigue Syndrome Symptom Rating Scale and the Quality of Life Index before the program, after program participants completed the group phase, and after program participants completed the one-an-one phase. It was hypothesized that the program would lead to improvements in quality of life and an overall reduction in symptom severity.

R_SI,JLTS. Linear growth models were estimated comparing program and control conditions overtime using random-effects regression analyses, Significant condition by time interactions were observed for the main outcomes of symptom severity and overall quality of life. Effect sizes for these interactions involving symptom severity (Cohen's d = 0.71) and overall quality of life (Cohen's d := .66) were moderate.

CONCLUSIONS. Findings indicate that consumer driven programs such as this one can have a positive impact on symptom severity and quality of life over time for individuals with chronic fatigue syndrome.

Taylor, R. R. (2004). Quality of life and symptom severity for individuals with chronic fatigue syndrome: Findings from a randomized clinical trial. *American Journal of Occupational Therapy,* 58, 35-43.

Renée R. Taylor, PhD, is Associate-Professor, University of Illinois at Chicago. Departmenf of Occupational Therapy (MC 811), College of Applied Health Sciences, 1919 West Taylor Street, 3rd Floor, Chicago, Illinois 60612-7250; rtaylor@uic.edu

This article was accepted for publication under the editorship of Betty Hasselkus.

Chronic fatigue syndrome is an often trivialized, yet profoundly disabling condition characterized by severe, unrelenting fatigue and a number of other physical and cognitive symptoms, such as sore throat, painful lymph nodes, headaches, muscle pain, multi-joint pain, unrefreshing sleep, post-exertion malaise, and memory and concentration problems (Fukuda et al., 1994). Much energy has been directed toward controversy over whether its cause is predominantly physical (labeled as a "real disease") or psychological (labeled as a "somatoform disorder or functional somatic syndrome"). Perhaps as a result, there has been a corresponding lack of attention to the impact of this syndrome on quality of life and everyday functioning. Moreover, rehabilitation professionals have been ill prepared to treat individuals with chronic fatigue syndrome, and remain just as baffled as physicians and other health care professionals regarding the true cause and nature of this condition (Mounstephen & Sharpe, 1997). Currently, there is no cure or widely accepted treatment for chronic fatigue syndrome, and only a small number of comprehensive, interdisciplinary rehabilitation programs exist (Essame, Phelan, Aggett, & White, 1998;Lim & Lubitz, 2002; Marlin, Anchel, Gibson, Goldberg, & Swinton, 1998; Pemberton, Hatcher, Stanley, & House, 1994). The purpose of this study was to examine the effects of one such program on symptom severity quality of life for individuals with chronic fatigue syndrome.

Quality of Life in Chronic Fatigue Syndrome

In comparison to other types of chronic illnesses such as multiple sclerosis, untreated hyperthyroidism, end-stage renal disease, and heart disease, individuals with chronic fatigue syndrome show markedly higher levels of disability, particularly in terms of physical fU11ctioning, role functioning, social functioning, vitality, and bodily pain (Anderson & Ferrans, 1997; Buchwald, Pearlman, Umali, Schmaling, & K1ton, 1996; Hardt et al., 2001; Komaroff et al., 1996; Schweitzer, Kelly, Foran, Terry, & Whiting, 1995). These physical, psychological, and social limitations, in conjunction with experiences of social stigma, public misunderstanding about chronic fatigue syndrome, and frequently strained relationships with health care providers, friends, and family members, have led individuals with chronic fatigue syndrome to report consistently low levels of quality of life (Anderson & Ferrans, 1997; Schweitzer et al., 1995).

In a modest but growing body of research, quality of life issues have been investigated in chronic fatigue syndrome samples (Anderson & Ferrans, 1997; Hardt et al., 2001; Schweitzer et al., 1995; Van Heck & DeVries, 2002). Findings from these studies demonstrate the wide-ranging impact of chronic fatigue syndrome on quality of life. Chronic fatigue syndrome affects daily life in a variety of domains, including: general health, physical and psychological health, role functioning, social and economic functioning, and family functioning. Anderson and Ferrans (1997) contend that, because chronic fatigue syndrome appears to involve both physiological and psychosocial elements, quality of life may ultimately influence the course of illness, improvement, and even recovery for individuals with chronic fatigue syndrome. Thus, evaluation of quality of life and treatment directed at improving its various dimensions are key components of any rehabilitation program (Anderson & Ferrans,' 1997).

Rehabilitation Programs Addressing Quality of Life

Quality of life is an- important, yet understudied outcome measure in clinical studies of cluonic fatigue syndrome (Scllweitzer et aI.,.J99S). As with most chronic illnesses and disabilities tor which medical treatment is at best palliative for specific symptoms, interdisciplinary or comprehensive rehabilitation efforts to reduce the' impact of illness on everyday physical, psychological, and social functioning currently represent a more realistic aim for individuals with chronic fatigue syndrome than efforts to locate a specific medical cure (Schweitzer et al.). A growing number of research studies have been initiated to test the efficacy of such integrative rehabilitation programs, and there is preliminary evidence that these programs improve specific aspects or consequences of the syndrome, such as fatigue (Chalder, Wallace, & Wessely, 1997), physical and occupational functioning (Essame, Phelan, Aggett, & White, 1998; Marlin, Anchel, Gibson, Goldberg, & Swinton, 1998; Pemberton et al., 1994; Sadlier, Phil, Evans, Phillips, & Broad, 2000), and psychological distress (Chalder, Wallace, & Wessely, 1997; Soderberg & Evengard, 2001).

Only one of these studies, a preliminary study of multidisciplinary approaches to therapy (Sadlier, Phil, Evans, Phillips, & Broad, 2000), demonstrated a specific, positive effect of an integrative rehabilitation program on quality of life. In this study, patients with chronic fatigue syndrome received a program consisting of heart rate monitoring and fitness training, cognitive behavior therapy, meditation techniques, and where necessary, breathing retraining. All patients achieved some degree of self-defined recovery from chronic fatigue syndrome as a result of the program. Twelve patients recorded a mean improvement in their own individual lists of chronic fatigue syndrome symptoms at baseline of 61 %, eight demonstrated an improvement in quality of life, five reported a return to full functioning, and two returned to school or work and regular exercise. All patients who participated at follow-up reported either continued improvements or maintenance of a well state.

This and other outcomes studies of comprehensive rehabilitation programs for individuals with chronic fatigue syndrome (Chalder, Wallace, & Wessely, 1997; Essame et al., 1998; Marlin et aI.; 1998; Pemberton et al., 1994; Sadlier et aI., 2000; Soderberg & Evengard, 2001) carry a number of limitations. First, all of the studies conducted in this area are either pilot studies, or offer only preliminaly evidence of program efficacy. They are also limited by small sample size, nonrandomization, the lack of a control group, or all three. Moreover, many utilize short-term models of care, and some have argued that treatment effects may be attenuated as a result (Soderberg & Evengard).

The Chronic Fatigue Syndrome Empowerment Project (Taylor & Jason, 2002) is a federally funded research project designed to develop and evaluate the effects of a comprehensive, consumer-driven rehabilitation program for individuals with chronic fatigue syndrome. It was designed to improve quality of life and reduce symptom severity for individuals with chronic fatigue syndrome through both group and individualized peer counseling. At the beginning of the program, participants set personal goals for wellness and vote on educational topics pertinent to chronic fatigue syndrome. Following an initial focus group, participants receive 4 months of illness management groups covering a number of topics relevant to the management of chronic fatigue syndrome (part 1), followed by a 7-month one-on-

one self-advocacy training period during which they continue to set and attain goals and also learn and practice strategies for independent living (part 2)'

The central aim of this study was to evaluate the cumulative outcomes of this two-part program in terms of quality of lite and symptom severity over time. Individuals with chronic fatigue syndrome were randomly assigned to either an immediate program group or a delayed program control group and evaluated concurrently at three time points. It was hypothesized that the program would lead to an overall reduction in symptom severity and improvements in quality of life over time for individuals in the program as compared to controls (i.e., program condition by time interaction).

Method

Design

Participants were randomly assigned to either an immediate program condition or a delayed-program control condition. Participants in the immediate program condition first participated in eight sessions of an illness-management group, occurring biweekly over a period of 4 months. Following a post-group assessment that occurred during a 1-month break period, program participants then, completed 7 months of one-on-one peer counseling, followed by another assessment. Delayed program controls waited to receive the program and only completed the two assessments during this 12-month period. They are currently receiving the program and results from their participation will be forthcoming in future publications.

Measures of the primary outcomes, symptom severity, and overall quality of life were administered by research staff not involved in the intervention and blinded to group assignment. Measures were administered uniformly to both experimental and control participants at the same three time points throughout the intervenrion: (1) at baseline; (2) within 1 month after participants in the immediate program condition completed the group phase; and (3) within 1 month after participants in the immediate program condition completed the one-on-one phase.

Participants

Fifty-two adults were recruited from the following sources: (1) focal chronic fatigue syndrome self-help organizations and Chicago-area physicians specializing in the treatment of people with chronic fatigue syndrome; and (2) advertisements posted in chronic fatigue syndrome newsletters, Chicago-area newspapers, on chronic fatigue syndrome Web sites and Listservs, and on a local cable TV station. Prospective participants underwent informed consent by receiving and signing a consent form, receiving a follow-up phone call to clarify all procedures in the study and answer any questions, and returning the form in the mail. All recruited adults underwent a screening process to confirm their self-reported diagnosis of chronic fatigue syndrome. This process involved four steps: (1) participants completed the Chronic Fatigue Syndrome Screening Questionnaire (Jason et aI., 1997) to evaluate for the presence, frequency, and severity of chronic fatigue syndrome symptoms according to the current U.S. diagnostic criteria (Fukuda et aI., 1994); participants then completed a semistructured psychiatric interview, the Structured Clinical Interview for the DSM-IV (SCID) (First, Spitzer, Gibbon, & Williams, 1995), administered by a licensed clinical psychologist to rule out psychiatric conditions that would exclude an individual from a chronic fatigue syndrome diagnosis according to the U.S. criteria (Fukuda et ai., 1994); (3) collection of past medical records documenting a diagnosis of chronic fatigue syndrome by a physician; and (4) independent physician review of results from the Chronic Fatigue Syndrome Screening Questionnaire, the psychiatric interview, and the medical. records to determine whether the potential participants met chronic fatigue syndrome criteria (Fukuda et al.).

As a result of the screening process, a diagnosis of chronic fatigue syndrome according to the current research diagnostic criteria (Fukuda et al., 1994) was confirmed for 50 individuals. The two subjects that did not meet the current criteria (Fukuda et al.) were excluded for the following reasons: one was determined to have an exclusionary medical condition (untreated hyperthyroidism) and the other subject did not meet symptom frequency criteria according to the Fukuda et al. requirement of four or more associated symptoms of chronic fatigue syndrome. Three of the remaining 50 individuals refused random assignment and were therefore not included in the statistical analyses of outcomes. Therefore, the final sample size was 47 individuals with chronic fatigue syndrome, of which 23 were randomly assigned to the immediate program group and 24 were assigned to the delayed program control group. Random assignment was completed using the SPSS for Windows Version 11.0 Random Variable Uniform Function. Program adherence was good and there were no dropouts during this program period. Table 1 presents sociodemographic characteristics of the sample.

Program Description

The program took place within a center for independent living that employed two peer counselors with chronic fatigue syndrome. The initial idea, structure, and framework for the program were developed using participatory action research. *Participatory action research* provides a

framework in which people with disabilities can take an active role in designing and conducting research (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). Empowerment theory (Rappaport, 1994), embraced by many occupational therapists, offered the underlying conceptual framework for the program. Contrary to the medical model of service delivery in which the patient becomes dependent on the provider for treatment, *empowerment theory* teaches self reliance and reliance on peer networks in solving problems. This project applied the principles of empowerment and participatory action research to its design, implementation, evaluation, and dissemination. The structure and logistical elements were developed conjointly by members of the local self-help organization serving individuals with chronic fatigue syndrome, staff of the center for independent living, and researchers with expertise in the study of chronic fatigue syndrome.

Program participants first participated in eight sessions of an illness-management group, occurring biweekly over a period of 4 months. This group was co-led by two individuals, a peer counselor and the author. The first part of each group session (hour 1) consisted of individual check-ins and reporting on self-monitored goal attainment. In the second part of each group session (hour 2), participants participated in an educational lecture and discussion of self-selected, chronic fatigue syndrome-relevant topics. Similar group structures have been used with individuals with other types of chronic conditions, such as Rheumatoid Arthritis (Lorig et al., 1999). In our program, group topics included activity pacing using the Envelope Theory (Jason et aI., 1999), cognitive coping skills training, relaxation and meditation training, employment issues and economic self-sufficiency, personal relationships, traditional and complementary medical approaches, and nutritional approaches.

Interestingly, many of the educational group topics selected by participants and known by individuals in the chronic fatigue syndrome patient community contained features of jnterventions used in occupational therapy. For example, Envelope Theory (Jason et al., 1999; Pesek, Jason, & Taylor, 2000) combines energy conservation and activity pacing. It posits that .individuals with chronic fatigue syndrome who overexert themselves and push the limits of their energy resources might need to reduce their activity levels, whereas those who are not active enough might need to increase their activity levels. Over time, clients learn to prioritize activities, use adaptive equipment, approach tasks from an energy conservation perspective, attend more carefully to bodily signals, and respond to those signals by altering their behaviors when necessary.

Following the 4-monrh period of illness-management group sessions (part 1), immediate program participants received seven momhs of peer counseling, which consisted of self-advocacy training, continued moniroring of goal attainment, and ongoing case coordination services by one of the peer counselors (patt 2). Resource funds in the anlounr of $300 pel' participant were provided to each participanr to support goal attainment, service acquisition, and local travel needs. In order to obtain the funds, participants were required to state how the financial expenditUre would facilitate goal attainment and independent living. A detailed description of the intervention program is presented elsewhere (Taylor & Jason, 2002).

Measures

Screening Measures. The *Chronic Fatigue Syndrome 5Ji:reming Questionnaire* Oason et a!., 1997) is a combination of existing and new measures including: (1) sociodemographic characteristics; (2) the Fatigue Scale (Chalder et aI., 1993); (3) the Chronic Fatigue Syndrome Symptom Rating Form, and questions assessing symptoms of chronic fatigue syndrome, quality, and duration of fatigue. Scoring of the Chronic Fatigue Syndrome Symptom Rating Form is described.below. The other questions assessing symptoms of chronic fatigue syndrome, quality, and duration of fatigue are scored according to the Fukuda et al. (1994) criteria. This screening scale has demonstrated high discriminant validity and excellent test-retest and interrater reliability Oason et aI., 1997).

The *Structured Clinical Interview for DSM-IV* (SCID; First et aI., 1995). The SCID is a professionally administered, semistructured psychiatric interview that was used to diagnose Axis I psychiatric disorders according to DSM-IV criteria. The SCID is appropriate for use with individuals with chronic fatigue syndrome because it allows tor clinical judgment in the assignment of symptoms to psychiatric or medical categories, a crucial distinction to make in diagnosing chronic fatigue syndrome (Friedberg & Jason, 1998; Taylor & Jason, 1998). Symptoms within each diagnostic category are scored as either absent, subthreshold, or present, and all symptoms that are present are counted toward the diagnostic tally as it conforms to DSM-IV criteria. A recent psychodiagnostic study (Taylor & Jason) validated the use of the SCID in a sample of individuals with chronic fatigue syndrome.

Outcome Measures

The Chronic Fatigue Syndrome Rating Form

Participants were asked to complete the Chronic Fatigue Syndrome Symptom Rating Form (Jason et al., 1997). Using this form, participants rate the severity of their fatigue and the severity of the eight chronic fatigue syndrome

definitional symptoms (Fukuda et aI., 1994) on a 1 DO-point scale, with 0 = no pain or problem and 100 = severe pain or problem. In a previous study Uason et al., 1997), a modified version of this form was demonstrated to have high test-retest reliability over a 2-week period (test-retest agreement: 76%-92%).

The *Quality of Life Index.* The Quality of Life Index (Ferrans & Powers, 1985; 1992) is a 72-item scale that was used to measure a primary outcome, perceived overall quality of life, among study participants. It is a valid and reliable measure that has been used effectively with samples of individuals with chronic fatigue syndrome (Anderson & Ferrans, 1997). The Quality of Life Index also measured secondary outcomes of quality of life in four major domains: health and functioning, social and economic, psychological-spiritual, and family. This instrument differs from most other measures in its acknowledgement that individuals place different priority on different aspects of life quality. What one person considers a disability may merely represent a nuisance for another (Ferrans, 1990). The index was designed to account for the observation that people differ with respect to which aspects of life quality they value the most such that life quality dimensions do not impact equally on perceptions of overall quality of life. It is comprised of two corresponding sections. One measures a person's satisfaction with 34 aspects of life on a six-point Likert-type scale (ranging from "very dissatisfied" to "very satisfied"), and the other measures the importance of those same aspects to the individual on a similar six-point Likert-type scale (ranging from "very unimportant" to "very important"). Final scores range from 0 to 30, and they are computed based on weighting each satisfaction response with paired importance response. Higher scores indicate higher life quality. Test-retest reliability for the Quality of Life Index has been found to be adequate, ranging between 0.81 and 0.87 (Ferrans & Powers, 1985, 1992).

Statistical Analyses

Given the nested design of this study (i.e., observations nested within individuals), linear growth models were estimated comparing program and control conditions for each outcome (quality of life and its subdomains, and symptom severity) using random-effects regression analyses. This approach was selected over a repeated measures analysis of covariance (ANOVA) because it more accurately models the effects of interest, which is change over time according to condition.

All analyses were performed using Hierarchical Linear Modeling (HLM 5; Raudenbush, Bryk, Cheong, & Congdon, 2000). These models consisted of level-l intercepts (set to the final wave of data) and slopes (i.e., changes over time), each of which is allowed to vary across individuals (i.e., has a random component). Program condition was treated as a fixed level-l effect. These random-effects regression models were used to test the cumulative effects of both the group phase and the one-on-one phase of the program over time in immediate program participants as compared with controls. Testing this nested model allowed for the examination of the hypotheses that participants in the immediate program condition would demonstrate significantly greater change in outcomes over time (i.e., program condition by time interaction), resulting in significantly higher quality of life and significantly lower symptom severity at the end of the intervention phase (i.e., program condition main effect). To test for the possibility that subjects' baseline fatigue severity may have affected program outcomes, baseline fatigue severity was initially included as a covariate at Level 2. Findings remained unchanged, so the covariate was removed from the model. To aid in the determination of the clinical significance of observed statistical differences, effect sizes (Cohen's d) were calculated (Rosenthal & Rosnow, 1991). Effect size measures the magnitude of treatment effects independent of sample size.

Results

Sociodemographic Characteristics

To test for sociodemographic differences between program and control conditions, a preliminary analysis of these characteristics was conducted. Results from *chi-square* and t-test analyses revealed no significant sociodemographic differences. Descriptive data are presented in Table 1.

Symptom Severity

The first model tested the effects of time and program condition on symptom severity. Analysis of symptom severity revealed a Sigllific.1Jlt time by condition interaction (b = -0.78, $[SE$ = 0.32], t [45] = -2.39, $P < 0.05$). The effect size was moderate (Cohen's d = 0.71). Individuals who received the program reported a statistically significant decrease in symptom severity over time relative to those in the control group, who reported a small increase (see Figure 1). Means and standard deviations for each assessment time point according to condition are presented in Table 2.

Quality of Life

Models for overall quality of life and four subdomains serving as secondary outcomes (health and functioning; social 311d economic; psychological and spiritual; and family) were tested. In each model, the effects of time (Levell) and condition (Level 2) were tested as predictors, and the intercept was first centered at Wave 3 in order to most conservatively

Table 1. Descriptive Data on Sociodemographic Characteristics of Participants With Chronic Fatigue Syndrome According to Rehabilitation Program Condition

	Comparison Groups	
	Immediate Program Participants $n = 23$	Delayed Program Controls $n = 24$
	f (%)	*f* (%)
Work Status		
Full-time work	2 (9%)	5 (21%)
Part-time work	5 (22%)	2 (8%)
Not working	16 (70%)	17 (71%)
Socioeconomic Status		
Low	5 (22%)	7 (29%)
Middle	15 (65%)	11 (46%)
High	3 (13%)	6 (25%)
Gender		
Female	21(91%)	24 (100%)
Male	2 (9%)	0 (0%)
Marital Status		
Never Married	7 (30%)	4 (17%)
Married	7 (30%)	9 (38%)
Divorced, Widowed, Separated	9 (39%)	11 (46%)
Minority		
Minority	4 (17%)	4 (17%)
Non Minority	19 (82%)	20 (83%)
	M (SD)	*M* (SD)
Age	49.0 (10.9)	44.9 (9.7)

f = frequency
M = mean
SD = standard deviation

Table 2. Means and Standard Deviations for Symptom Severity and Quality of Life for Participants With Chronic Fatigue Syndrome According to Program Condition

	Comparison Groups	
	Immediate Program Participants $n = 23$ *M* (SD)	Delayed Program Controls $n = 24$ *M* (SD)
Symptom Severity*		
Assessment 1	15.1 (3.0)	14.2 (2.8)
Assessment 2	14.4 (3.5)	14.3 (2.7)
Assessment 3	13.9 (3.5)	14.8 (2.8)
Overall Quality of Life*		
Assessment 1	13.1 (4.3)	14.0 (3.9)
Assessment 2	13.2 (3.8)	14.6 (4.8)
Assessment 3	15.7 (3.7)	14.6 (4.1)
Quality of Life—Health and Functioning		
Assessment 1	12.9 (1.6)	13.1 (1.7)
Assessment 2	12.8 (1.8)	13.6 (2.1)
Assessment 3	14.1 (1.7)	13.6 (1.8)
Quality of Life—Social and Economic		
Assessment 1	15.0 (1.2)	15.4 (0.7)
Assessment 2	15.2 (0.8)	15.5 (1.0)
Assessment 3	15.6 (0.8)	15.5 (0.9)
Quality of Life—Psychological and Spiritual		
Assessment 1	15.0 (1.2)	15.0 (1.1)
Assessment 2	15.0 (1.1)	15.2 (1.3)
Assessment 3	15.5 (1.1)	15.1 (1.2)
Quality of Life—Family*		
Assessment 1	15.4 (0.9)	15.7 (1.0)
Assessment 2	15.4 (1.0)	15.5 (1.0)
Assessment 3	15.6 (0.8)	15.5 (0.9)

M = mean
SD = standard deviation
* Indicates a significant time by condition interaction at the $p < 0.05$ level

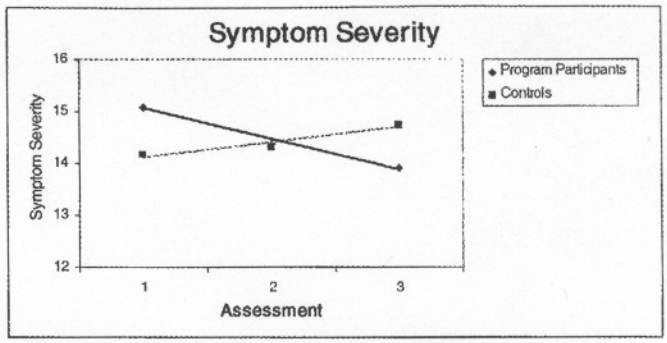

Figure 1. Symptom Severity for Program Participants and Controls With Chronic Fatigue Syndrome ($N = 47$). This figure depicts results of the Chronic Fatigue Syndrome Symptom Rating Form across the three time points according to program condition. Higher ratings indicate greater symptom severity.

test the outcomes of the program over time. Analysis of overall quality of life revealed a significant time by condition interaction ($b = 0.98$ [$SE = 0.44$], t [45] = 2.22, $p < 0.05$). The effect size was moderate (Cohen's d = 0.66), and the difference in Assessment 1 and Assessment 3 mean scores between groups was 2.65, which is higher than published mean difference scores (2.17–2.55) in other outcomes studies using the Quality of Life Index (Bliley & Ferrans, 1993; Rannestad, Eikeland, Helland, & Qvarnstrom, 2001). As indicated in Figure 2, individuals who received the program reported significantly higher quality of life over time, whereas quality of life for individuals in the control group remained stable over time.

Similarly, the analysis of quality of life with respect to family functioning revealed a significant time by condition interaction ($b = 0.18$ [$SE = 0.07$], t [45] = 2.49, $p < 0.05$). Program participants demonstrated significantly higher quality of life over time with respect to family functioning, in comparison to controls, whose scores decreased. The effect size was moderate (Cohen's d = 0.74), but the increase in mean scores at follow-up was relatively small, as evident in Table 2. This particular finding should be interpreted with caution and replicated in future work. If future work reveals that the effect on rate of change over time is maintained, it will then be possible to conclude that this effect

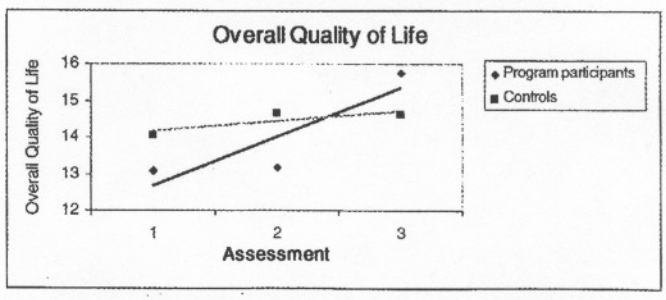

Figure 2. Overall Quality of Life for Program Participants and Controls With Chronic Fatigue Syndrome ($N = 47$). This figure depicts results of the Quality of Life Index total score across the three time points according to program condition. Higher ratings indicate greater quality of life.

results in a clinically meaningful change in participants' family functioning.

There were no other significant main or interaction effects of time and condition for the other three quality of life subdomains. Means and standard deviations for all quality of life outcomes at each assessment time point according to condition are presented in Table 2.

Because there were only interaction effects and no main effects of condition, the regression models were retested centering the intercept at Wave 1, rather than at Wave 3. This allowed us to test for initial group differences on the outcome variables. These models showed no significant group differences at Wave 1, suggesting that the effects were due to the program rather than to any baseline differences In means.'

Conclusions

This study constitutes the first randomized clinical trial measuring the effects of an integrative, consumer-driven rehabilitation program on quality of life and symptom severity for individuals with chronic fatigue syndrome. Findings from this study indicate that the program tested had a positive impact on primary outcomes of symptom severity and overall quality of life. Only one other study of an integrative rehabilitation program (Sadlier et al., 2000) demonstrated a specific, positive effect on quality of life ror individuals with chronic fatigue syndrome, but the generalizability of results was limited by nonrandomization and the lack of a control group. It is likely that the effects from the present study were clinically significant, and the program may be transportable to occupational therapy settings able to incorporate consumer-driven models of care.

Findings for improved family quality of life were signficanr but modest, and conclusions about clinical significance would be premature at this point. Of relevance is that a recent, uncontrolled study of family-focused cognitive behavioral therapy for chronic fatigue syndrome documented a positive effect of the therapy on improving functioning and reducing fatigue (Chalder, Tong, & Deary, 2002). In the absence of such interventions, research suggests that family functioning and other forms of social support tend to decline over time, leaving most individuals with chronic fatigue syndrome socially isolated (Anderson & Ferrans, 1997). As evident in Table 2, individuals in the control condition did demonstrate a small decline in family quality of life over the course of a year, while individuals who received our program reported slight improveinent in family quality of life. Additional longitudinal research with repeated measures of family quality of life is necessary to test whether these distinctive trends are clinically significant and endure over time.

Based on findings presented in Table 2, it appears as though program participants demonstrated greatest improvement at Assessment 3 (the second follow-up) rather than at Assessment 2. Further follow-up testing of these effects 4 and 12 months following the program will be conducted in fUture studies to determine whether program participants continue to improve with time, and the extent to which outcomes of the program endure over time. Findings for continued improvement over time (defined as an enduring or cumulative positive effect of treatment) are not unusual in chronic fatigue syndrome studies, and a similar temporal pattern of effects has been found in other studies of integrative rehabilitation programs or cognitive behavioral interventions with follow-up periods (Bonner, Ron, Chalder, Butler, & Wessely, 1994; Butler, Chadler, Ron, & Wessely, 1991; Marlin et al., 1998). It is possible that, in some patients, the disabling, severe nature of the fatigue, cognitive difficulties, and multiple physical symptoms of chronic fatigue syndrome influence the rate of responsiveness to certain kinds of rehabilitative interventions, such as those often used by occupational therapists, which focus on lifestyle change, coping, and changes in role functioning. Depending upon an individual's readiness for change, these types of changes may not occur until late in the intervention, and any resulting changes in quality of life or symptom severity may not reveal themselves until months after the intervention has ended.

Findings from this study carry a number of implications for occupational therapy practice. First, they illustrate that integrative, community-based rehabilitation programs emphasizing psychoeducation, consumer input, goal setting, and self-advocacy can have a modest but clinically significant positive effect on individuals with chronic fatigue syndrome, not only in terms of quality of life, but also in terms of symptom reduction. Generally speaking, participatory, community-based models of occupational therapy service may offer a viable alternative to more medicalized approaches to therapy, which generally focus on correcting isolated deficits or improve functioning in a single area. In participatory approaches, the occupational therapist can assume a number of interrelated roles. These may range from assisting clients to identify their own treatment goals and self-monitor their progress, to inviting clients with particular strengths or experience to co-lead a rehabilitation program or serve as peer counselors with supervision, to establishing an active working relationship with local centers for independent living so that clients can learn principles of self-advocacy, disability rights, and gain access to community-based services and resources that facilitate inde pendent living. All of these actions were

carried out effectively by the peer counselors in the present study.

The use of peer counselors in the rehabilitation process can be a powerful instrument for change. Participants in the program reported that peer counselors offered a unique level of empathy and shared an abundance of relevant real-world experiential information. This information ranged from sharing their own experiences with applying aspects of the illness management groups to their own lives, to sharing their struggles and aspects of their personal journeys with chronic fatigue syndrome, to helping clients navigate social systems of care (Le., applying for social security disability benefits, advocating for reasonable accommodation within the workplace, or applying for assistance to receive food delivery, electricity, gas, or housing). Occupational therapists in clinical practice and their clients may benefit from increased expertise, empathy, and knowledge acquired through direct collaboration with individuals with chronic fatigue syndrome that are supervised to function in peer counseling roles as members of a larger interdisciplinary treatment team. In sum, findings from this study suggest that integrative, peer-facilitated rehabilitation programs that focus on empowerment may lead to a decrease in symptom severity and an improvement in quality of life for individuals with chronic fatigue syndrome.

Acknowledgments

Funding for the Chronic Fatigue Syndrome Empowerment Project was provided by the U.S. Department of Education National Institute on Disability and Rehabilitation Research Grant #H133G000097 awarded to Dr. Renée Taylor of the University of Illinois at Chicago and Professor Leonard Jason of DePaul University in collaboration with Access Living and the Chicago Chronic Fatigue Syndrome Association. The author would like to thank Dr. Michael Schoeny for his assistance with statistical methods.

References

Anderson, J. S., & Ferrans, C. E. (1997). The quality of life of persons with 'chronic fatigue syndrome. *Journal of Nerllous ilnd Mental Diseases,* 185,359-367.

Balcazar, F. E., Keys, C. B., Kaplan, D. L., & Suarez-Baicazar, Y. (1998). Participatory action research and people with disabilities: Principles and Challenges. *CAnadian Journal of Rehabilitation.* 12, 105-112.

Bliley, Av., & Ferrans, C. E. (1993). Psychologic aspects of cardiovascular care.. Quality of life after coronary angioplasty. *Heart and Lung,* 22, 193-199.

Bonner, D., Ron, M., Chalder, T., Buder, S., & Wessely, S. (1994) Chronic fatigue syndrome: A follow-up study. *Journal of Neurolog)!, Neurosurgery and Psychiatry* 57, 617-621.

Buchwald, D., Pearlman, T., Umali, J., Schmaling, K., & KatOn, W. (1996). Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals. *American Journal of Medicine, 101,364-370.*

Butler, S., Chad IeI', T., Ron, M., & Wessely, S. (1991). Cognitive behavior therapy in the chronic fatigue syndrome. *Jottl'nal of Neurology and Neurosurgery Psychiatry* 54, 153-158.

Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, et al. (1993). Development of a fatigue scale. *Journal of Psychosomatic Medicine,* :37, 147-153.

Chalder, T., Tong, J., & Deary. (2002). Family cognitive behaviour therapy for chronic fatigue syndrome: an uncontrolled study. *Archi11es of Disease in Childhood,* 86, 95-97.

Chalder, T., Wallace, P., &Wessely, S. (1997). Self-help treatment of chronic fatigue in the community: A randomized controlled trial. *British Journal of Health Psychology,* 2,189-197.

Essame, C. S., Phelan, S., Aggett, P., & White, P. D. (1998). Pilot stUdy of a multidisciplinary inpatient rehabilitation of severely incapacitated patients with the chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome,* 4, 51-60.

Ferrans, C. E. (1990). Quality oflife: ConceptUal issues. *Seminars in Oncology Nursing,* 6, 248-254.

Ferrans, C. E., & Powers, M. J. (1985). Quality of life index: Development and psychometric properties. *Advances in Nursing Science,* 8, 15-24.

Ferrans, C. E., & Powers, M. J. (1992). Psychometric assessment of the Quality of Life Index. *Research in Nursing and Health,* 15, 29-38.

First, M. B., Spitzer, R. 1., Gibbon, M., & Williams, J. B. W. (1995). *Structtmd Clinical Inter1Jiew for DSM-IV Axis I Disorders-Patient edition.* New York: Biometrics Research Department. .

Friedberg, E, & Jason, L. A. (1998). *Understanding chronic fatigue syndrome: An empirical guide to assessment. and treatment.* Washington, DC: Anlerip111 Psychological Association.

Fukuda, K., Strauss, S. E., Hickie, I., Sharpe, M. c., Dobbins, J. G., & KomaroH: A(1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine,* 121, 953-959.

Hardt. J., Buchwald, D., Wilks, D., Sharpe, M., Nix, W. A, & Egle, V.T. (2001). Health-related quality of life in patients with chronic fatigue syndrome: An international study. *Journal ofPsycho.wrnatic Research,* 51,431-434.

Jason, L. A., Ropacki, M. T., Santoro, N. B., Richman, J.A., Heatherly, w., Taylor, R., et al. (1997). A screening scale for Chronic Fatigue Syndrome: Reliability and validity. *Journal of Chronic Fatigue Syndrome,* 3, 39-59.

Jason, L. A., Melrose, H., Lerman, A, Burroughs, V., Lewis, K., King, C. P., et al. (1999). Managing chronic fatigue syndrome: A case study. *MOHN.!ournah* 47, 17-21.

KomaroH: A L., Fagioli, L. R., Doolitde, T. H., Gandek, B., Gleit, M. A, Guerrierio, R. T., et at. (1996). Heahh statUs in patients with chronic fatigue syndrome and in general pop ulation and disease comparison groups. *American Journal of Medicine, 101,281-290.*

Lim, A., & Lubitz, L. (2002). Chronic fatigue syndrome:

Successful outcome of an intensive inpatienc programme. *Journal of Pediatric and C'MId Health,* 38. 295-299.

Lorig, K. R., Sobel, D. S., Stewart, A L., Brown, B. W. J" Bandura, A., Ritter, P., et al. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. *Medical Care,* 37(1),5-14.

Marlin, R. G., Anchel, H., Gibson, J. C, Goldberg, W. M., & Swinton, M. (1998). An evaluation of multidisciplinary intervention for chronic fatigue syndrome with long-term follow-up, and a comparison with untreated concrols. *American Journal of Medicine, 105,* 110S-114S.

Mounstephen, A., & Sharpe, M. (1997). Chronic fatigue syn drome and occupationaJ health. *Occupational Medicine,* 47, 217-227.

Pemberton, S., Hatcher, S., Stanley, P., & House, A (1994). Chronic fatigue syndrome: A way forward. *British Journal of Occupational Therapy,* 57, 381-383.

Pesek, J. R.,Jason, L. A, & Taylor, R. R. (2000). An empirical investigation of the envelope theory. *Journal of Human Behallior in the Social Environment,* 3, 59-77.

Rannestad, T., Eikeland, 0., HeJland, H., & Qvarnstrom, U. (2001). The quality oflife in women suffering from gynecological disorders is improved by means of hysterectomy. *Acta Obstretrica et Gynecologica Scandinavica, 80,* 46-5 J.

Rappaport, J. (1994). Empowerment. as a guide. to. doing research: Diversity as a positive value. In E. J. Trickett, R. J. Watts, & D, Birman (Eds.), *Human diversity: Perspectives on people in context.* San Francisco: Jossey-Bass.

Raudenbush, S., Bryk, A, Cheong, Y. E, & Congdon, R. (2000). *HLM* 5: *Hierarchical Lirtetlr and Nonlinear Modeling.* Lincolnwood, IL: Scientific Software International, Inc.

Rosenthal, R., & Rosnow, R L. (1991). *Essentials of behal/ioral mearch: Methods and data analysis* (2nd cd.). New York: McGraw Hill.

Sadlier, M., Phil, *D.,* Evans, J. R., Phillips, C, & Broad, A. (2000). A preliminary study into the effectiveness of multiconvergent therapy in the treatment of heterogeneous patients with chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome,* 7. 93-101.

Schweitzer, R.. Kelly, B., Foran, A, Terry. D., & Whiting, J. (1995). Quality of life in chronic fatigue syndrome. *Social Science and Medicine,* 41, 1367-1372.

Soderberg, S., & Evengard, B. (2001). Short-term group therapy for patients with chronic fatigue syndrome. *Psychotherapy and Psychosomatics, 70,* 108-111.

Taylor. R., & Jason, L. A (1998). Comparing the DIS with the SCID: Chronic fatigue syndrome and psychiatric comorbidity. *Psychology and Health: The International Rel/iew of Health Psychology,* 13, 1087-1104.

Taylor, R. R., & Jason, L. A (2002). Group intervention involving a client with chronic fatigue syndrome: A clinical case study. *Clinical Case Studies,* 1, 183-210.

Van Heck, G. L., & DeVries, J. (2002). Quality of life in patientS with chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome, 10,* 17-35.