

Long-term outcomes of an integrative rehabilitation program on quality of life: A follow-up study[☆]

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Abstract

Objective: To assess the long-term effects of an integrative rehabilitation program on the overall quality of life of individuals with chronic fatigue syndrome (CFS). **Methods:** This study utilized a within-subjects, repeated measures cohort design. Twenty-three subjects diagnosed with CFS attended eight sessions of an illness-management group followed by 7 months of goal-oriented, individualized counseling that occurred once weekly for 30 min per session. Quality of life was assessed at five time points (baseline, following the group phase, following the one-on-one phase, and

4 and 12 months following program completion). **Results:** A within-subjects repeated measures ANOVA revealed significant increases in overall quality of life for up to 1 year following program completion [$F(4, 21)=23.5, P<.001$]. **Conclusions:** Definitive conclusions about program efficacy are limited by design issues. However, findings suggest that the program may have led to improvement in quality of life for up to 1 year following program completion.

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Introduction

Chronic fatigue syndrome (CFS) is an often trivialized, yet disabling condition characterized by severe fatigue and a number of other physical and cognitive symptoms, such as sore throat, painful lymph nodes, headaches, muscle pain, multijoint pain, unrefreshing sleep, post-exertional malaise, and memory and concentration problems [1]. Studies show that quality of life is particularly and uniquely disrupted in CFS [2–6]. As with most chronic illnesses and disabilities for which medical treatment is palliative at best for specific symptoms, interdisciplinary or comprehensive rehabilitation efforts may offer the most pragmatic means of attempting to

reduce the impact of CFS on everyday physical, psychological and social functioning. In addition, these programs may offer individuals a means of managing a greater number of aspects and consequences of the syndrome for everyday life [2].

A small but increasing number of research studies have been initiated to test the efficacy of a range of different approaches to rehabilitation for individuals with CFS, including programs based on cognitive-behavior therapy, stress reduction training, supportive counseling and comprehensive care [7]. Preliminary evidence suggests that these programs may improve specific aspects or consequences of the syndrome, such as fatigue [8], physical and occupational functioning [9–12], and psychological distress [8,13].

Only one of these studies [12] examined quality of life as one of the primary outcomes, but because the researchers allowed participants to select their own outcomes, not all participants provided data on quality of life. In this study, participants with CFS received a program consisting of heart

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rate monitoring and fitness training, cognitive behavior therapy, meditation techniques and, where necessary, breathing retraining. All participants achieved some degree of self-defined recovery from CFS as a result of the program [12]. Twelve participants recorded a mean improvement of 61% in their own individual lists of CFS symptoms at baseline, 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 individuals 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 CFS carry a number of limitations. First, all of the studies conducted in this area have either been pilot studies, have not been replicated or have offered only preliminary evidence of program efficacy [7]. Primary outcome measures tend to differ across programs. Moreover, many programs utilize short-term models of care, and some have argued that treatment effects may be attenuated as a result [13]. A key limitation across studies is that there has been no consistent investigation of the long-term effects of these programs on the specific outcome of quality of life. For example, because outcomes were selected by participants in the Sadler et al. study [12], not all participants selected quality of life as a relevant outcome. This made it impossible to measure program-related change in quality of life over time using formal empirical methods.

Among programs that have been developed to improve functioning and symptoms, the program to be evaluated herein was a recently conducted, peer-facilitated rehabilitation program that took place within a center for independent living. Centers for independent living are community-based organizations that focus on issues of advocacy and independence for individuals with disabilities. The goal of the program was to improve quality of life and reduce symptom severity through psychoeducational groups and individualized peer counseling. A prior study [14] that evaluated preliminary outcomes of this program found that it led to significant improvements in overall quality of life for participants with CFS immediately following program completion. In the Taylor study [14], participants who received the program (immediate program group) were compared with participants who did not receive the program (delayed-program control group).

The aim of the present study was to evaluate whether the improvement in overall quality of life found in the Taylor study [14] was sustained by individuals in the immediate program group 4 and 12 months following program completion. It was hypothesized that the improvement in quality of life found immediately following participation [14] would be sustained by participants in the immediate program group for up to 1 year following completion. Because findings from the Taylor study [14] revealed no significant change in quality of life from baseline to the post-group phase, a specific prediction about the overall

pattern of change across all five time points was made. It was predicted that there would be no change in quality of life from baseline to the post-group phase (T1–T2), followed by an increase in quality of life from the post-group phase to the post-one-on-one phase (T2–T3), followed by a plateau from the post-one-on-one phase to the 4- and 12-month follow-up (T3–T5) periods.

Methods

Design

This study utilized a within-subjects, repeated measures design. Participants first attended eight sessions of an illness-management group, occurring biweekly over a period of 4 months and then completed 7 months of individualized peer counseling. Measures of overall quality of life were administered at five time points before, during and after the intervention period: at baseline (Time 1); within 1 month after participants completed the illness management group (Time 2); within 1 month after participants completed individualized peer counseling (Time 3); 4 months following assessment 3 (Time 4); and 8 months following assessment 4 (Time 5).

Participants

Participants were recruited from local CFS self-help organizations (62%), referred by physicians (25%) and recruited through advertisements posted in CFS newsletters, local newspapers, on CFS websites and listservs, and on a local cable TV station (13%) [14]. All participants provided informed consent and were screened [14] as meeting current international research criteria for CFS [1]. Forty-seven participants were involved in the original Taylor study [14], of whom 23 were randomly assigned to the immediate-program group and 24 were assigned to the delayed-program control group. Results of the current follow-up study only reflect within-subjects findings for the 23 individuals in the immediate-program group, since they were the only group that received two follow-up assessments upon completion of the program. Individuals in the delayed-treatment control group received usual medical care until the final year of the study, when they received the program in addition to continuing their usual medical care. Approval and funding for the program were scheduled to end immediately after the control group finished the program, so it was not possible to collect follow-up data on the control group. In the immediate program group, program adherence was good and there were no dropouts among participants.

Sociodemographic characteristics of the sample are presented in Table 1. The sample consisted mainly of nonminority women of middle to high socioeconomic

Table 1
Sociodemographic characteristics of the sample (n=23)

Variable	Frequency	Percentage
Sex		
Male	2	9
Female	21	91
Socioeconomic status		
High	3	13
Middle	15	65
Low	5	22
Marital status		
Married	7	30
Never married	7	30
Separated, widowed, divorced	9	39
Work status		
Working full-time	2	9
Working part-time	5	22
Not working	16	70
Minority		
Minority	4	17
Nonminority	19	82
	Mean	Standard deviation
Age	49	10.9

status. Most were not working and single (never married, separated, widowed or divorced).

Program description

The program was conducted by two peer counselors with CFS who were employed by a local center for independent living. The initial idea, structure and framework for the program were developed using participatory action research. 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 first 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, CFS-relevant topics. Similar group structures have been used with individuals with other types of chronic conditions, such as rheumatoid arthritis [15].

In our program, group topics included activity pacing, cognitive coping skills training, relaxation and meditation training, employment issues and economic self-sufficiency, personal relationships, traditional and complementary medical approaches, and nutritional approaches. Following the 4-month period of illness-management group sessions (Part 1), participants received 7 months of peer counseling, which consisted of self-advocacy training, continued monitoring of goal attainment and ongoing case coordination services by one of the peer counselors (Part 2). A detailed description of the intervention program is presented elsewhere [14].

Measure

Quality of Life Index

The Quality of Life Index [16,17] was used to measure participants' perceptions of health-related quality of life. The Quality of Life Index is a valid and reliable [16,17], 72-item scale that is commonly used in CFS studies [3]. More information about this measure is provided in a previous study [14].

Statistical analyses

Basic descriptive statistics were used to describe the sociodemographic characteristics of the sample.

For the inferential analysis, a within-subjects, repeated-measures analyses of variance (ANOVA) was performed to measure the pattern of change in overall quality of life over time. Time served as the within-subjects factor, and it encompassed the results from quality of life assessment for the following five waves of data collection: (T1) baseline; (T2) mid-program (i.e., between group and individual phases), (T3) immediate post-program; (T4) 4-month follow-up; and (T5) 12-month follow-up (i.e., 8 months following T4). For the repeated-measures ANOVA, there were missing data for one subject because it was not possible to locate the subject for the third and fourth assessment time points.

Using the ANOVA, we tested a planned contrast that reflected a pattern of change over time that we hypothesized would most likely fit the mean score data. This pattern predicted no change in quality of life from baseline to the post-group phase (T1–T2), followed by an increase in quality of life from the post-group phase to the post-one-on-one phase (T2–T3), followed by a plateau from the post-one-on-one phase to the 4- and 12-month follow-up (T3–T5) periods.

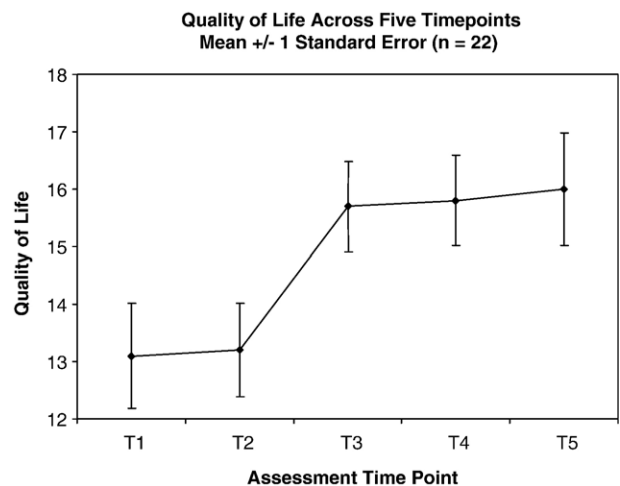


Fig. 1. Quality of life across five time points.

A preliminary analysis of relationships between each of the sociodemographic variables and quality of life was conducted. No significant relationships between these variables and quality of life emerged.

Results

Findings from the repeated-measures ANOVA indicated that the initial increase in quality of life immediately following program completion that was found in the Taylor study [14] was sustained 4- and 12-months following program completion [$F(4, 21)=23.5, P<.001$]. The total increase in quality of life over the project period from a baseline score of 13 to a final score of 16 reflects a 23% change over time. Fig. 1 presents the means and standard error intervals for overall quality of life at all five time points. As predicted, the pattern of growth involved stable level of quality of life from baseline to the post-group phase (T1–T2), an increase from the post-group phase to the post-one-on-one phase (T2–T3), followed by a relative plateau from the post-one-on-one phase to the 4- and 12-month follow-up (T3–T5) periods.

Discussion

This study evaluated the long-term effects of an integrative consumer-driven rehabilitation program on quality of life for individuals with CFS. Findings indicate that the program led to overall improvement in quality of life, and this improvement was sustained for 1 year following completion of the program. One other study of an integrative rehabilitation program [12] reported specific, immediate positive effects on quality of life, but the present study is the first to provide follow-up data in this domain. Findings also highlight the importance of performing follow-up assessments when determining the effectiveness of programs for individuals with CFS, especially when examining the effects of a given program on the relatively stable construct of quality of life.

Given that significant improvement in quality of life was not immediately evident until after the one-on-one phase, it is possible that it was the cumulative nature of our program that led to overall outcomes and their endurance over time. It is equally likely that the group phase did not produce an effect on quality of life. The key finding introduced in this paper emphasizes the relatively long-term duration of the program's effect on quality of life, resulting in a 23% increase in quality of life regardless of whether this effect is attributable to both phases or to just the one-on-one phase. It is possible that both the comprehensiveness and the relatively long duration of the program (12 months) influenced the sustained positive outcomes observed 1 year later.

This study carried a number of limitations. First, the sample size was small, and the fact that we did not have

follow-up data on control subjects necessitated the use of a within-subjects design for this follow-up study. The lack of follow-up data available for the controls limited the extent to which findings could be attributable to the intervention. Moreover, the limitation in sample size prevented us from performing a components analysis. Such an analysis would have allowed us to determine the independent effectiveness of each of the program phases (group intervention vs. one-on-one intervention). Future studies should tease apart not only the effectiveness of each of the approach but also how these two approaches may influence each other to impact the effectiveness of integrative rehabilitation programs for individuals with CFS. Also of note is that over half of the participants (62%) were recruited from self-help groups. This may have introduced selection bias into the sample. In addition, we were unable to control for differences in usage of medications, medical care, nutritionals and complementary medical care over the course of the follow-up period, and this may have influenced findings.

Although definitive conclusions about program efficacy are limited by the absence of a control group, findings suggest that, at a preliminary level, the rehabilitation program had a positive effect on the health-related quality of life of the participants for up to 1 year following program completion. These findings may have important implications for rehabilitation professionals working with people with CFS. Specifically, this program utilized a client-centered approach to goal setting that was reinforced by peer feedback and support for goal attainment. It also employed self-advocacy training, education and ongoing peer mentoring on topics associated with illness management, and support for access to community-based resources, such as personal assistants and specialized transportation. Although it remains unclear which of these specific strategies had the greatest impact on positive outcomes, the study offers some preliminary evidence for the potential effectiveness of their use in clinical settings. Continued research is recommended to determine the specific program elements and characteristics that led to the positive outcome of improved quality of life. In addition, rehabilitation professionals might consider ways to implement community-based approaches, such as employment of peer counselors and referral to centers for independent living, within more medically oriented rehabilitation settings. This aim represents an important and sometimes underutilized aspect of the rehabilitation process.

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References

- [1] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Ann Intern Med* 1994;121:953–9.
- [2] Schweitzer R, Kelly B, Foran A, Terry D, Whiting J. Quality of life in chronic fatigue syndrome. *Soc Sci Med* 1995;41:1367–72.
- [3] Anderson JS, Ferrans CE. The quality of life of persons with chronic fatigue syndrome. *J Nerv Ment Dis* 1997;185:359–67.
- [4] Buchwald D, Pearlman T, Umali J, Schmaling K, Katon W. Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals. *Am J Med* 1996;101:364–70.
- [5] Hardt J, Buchwald D, Wilks D, Sharpe M, Nix WA, Egle UT. Health-related quality of life in patients with chronic fatigue syndrome: an international study. *J Psychosom Res* 2001;51:431–4.
- [6] Komaroff AL, Fagioli LR, Geiger AM, Doolittle TH, Lee J, Kornish RJ, et al. An examination of the working case definition of chronic fatigue syndrome. *Am J Med* 1996;100:56–64.
- [7] Taylor RR. Chronic fatigue syndrome: traditional and community-based approaches to rehabilitation. *Health Soc Care Community* 2004;12:174–85.
- [8] Chalder T, Wallace P, Wessely S. Self-help treatment of chronic fatigue in the community: a randomized controlled trial. *Br J Health Psychol* 1997;2:189–97.
- [9] Essame CS, Phelan S, Aggett P, White PD. Pilot study of a multidisciplinary inpatient rehabilitation of severely incapacitated patients with the chronic fatigue syndrome. *J Chronic Fatigue Syndr* 1998;4:51–60.
- [10] Marlin RG, Anchel H, Gibson JC, Goldberg WM, Swinton M. An evaluation of multidisciplinary intervention for chronic fatigue syndrome with long-term follow-up, and a comparison with untreated controls. *Am J Med* 1998;105:110S–4S.
- [11] Pemberton S, Hatcher S, Stanley P, House A. Chronic fatigue syndrome: a way forward. *Br J Occup Ther* 1994;57:381–3.
- [12] Sadlier M, Phil D, Evans JR, Phillips C, Broad A. A preliminary study into the effectiveness of multiconvergent therapy in the treatment of heterogeneous patients with chronic fatigue syndrome. *J Chronic Fatigue Syndr* 2000;7:93–101.
- [13] Soderberg S, Evengard B. Short-term group therapy for patients with chronic fatigue syndrome. *Psychother Psychosom* 2001;70:108–11.
- [14] Taylor RR. Quality of life and symptom severity for individuals with chronic fatigue syndrome: findings from a randomized clinical trial. *Am J Occup Ther* 2004;58:35–43.
- [15] Lorig KR, Sobel DS, Stewart AL, Brown BJ, Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. *Medical Care* 1999;37:5–14.
- [16] Ferrans CE, Powers MJ. Psychometric assessment of the Quality of Life Index. *Res Nurs Health* 1992;15:29–38.
- [17] Ferrans CE. Quality of life: conceptual issues. *Semin Oncol Nurs* 1990;6:248–54.