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Employment and Health Status Changes among Women with Fibromyalgia: A Five-Year Study

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Abstract

Purpose—To assess changes in health status among women with fibromyalgia (FM) over five years and determine whether baseline employment status influences health outcomes adjusting for other baseline factors.

Methods—287 female FM patients were recruited from a national sample of rheumatologists. Participants were interviewed by phone at baseline and annually for four years. Data were collected on pain and fatigue on 100 point visual analogue scales; Center for Epidemiologic Studies Depression Scale (CESD) and Modified Health Assessment Scale (MHAQ), demographic characteristics and employment status. 211 participants remained at the end of the study. Data were analyzed using multi-level modeling techniques with SAS statistical package. Boot strap methods adjusted for the cluster sampling.

Results—The mean age of participants was 47 (sd=11), participants had 14 (sd=2) years education, 90% were White, 50% employed, 64% were married with median household incomes of $50,000 or higher. Mean health status scores at baseline were 57.2 (sd=24) for pain; 75.4 (sd=22) for fatigue; 22.9 (sd=13) for depression; and 0.73 (sd=0.5) for MHAQ. Multi-level modeling adjusting for demographic characteristics indicated that all health status measures declined significantly over time with the exception of pain. Rates of change varied from −1.22 for fatigue to −0.03 for MHAQ. Except for pain, those who were employed at baseline had better health status over time. The employment and time interaction was not significant indicating that health status changed at the same rate regardless of employment status. Other significant factors were age and income. There were significant interactions between time and race, duration of disease and age.

Conclusions—Employed women with FM have better health status at baseline and maintain that advantage over time. Employment does not seem to provide a protective health benefit.

Fibromyalgia syndrome (FM) is a highly prevalent rheumatic disorder affecting 5% to 7% (1) of the US population, mostly women (2–4) FM is defined as widespread pain accompanied by 11 or more of 18 specific tender point sites (5). Other symptoms include fatigue, sleeplessness and stiffness. The etiology of FM has not been confirmed, but several theories suggest that FM is a pain amplification disorder (6–8) resulting from the dysregulation of central pain processing. Relatively little is known about the progression of FM over time. The few longitudinal studies of FM indicate that total remissions are rare. Findings are inconsistent about long-term prognosis as some studies demonstrate general improvement in symptoms and functional status over time while others show no improvement or worsening of condition (9–18).

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We previously reported on the cross-sectional relationships between employment and health status among women with FM (19). Based on community studies of women and general health status, we hypothesized that employment would provide a health benefit for women with FM (20–30) Employed women with FM reported better health status than those who were not employed. Although the results were suggestive, it was unclear whether employment provided a health benefit or whether the women with S were employed because they were healthier. The purpose of this study was to assess health status changes among women with FM over a five year period and to determine whether baseline employment status influenced health outcomes adjusting for demographic factors.

Methods

Sample

A two-step methodology was used to recruit women with FM. First, a national sample of rheumatologists was randomly selected from the American College of Rheumatology (ACR) membership. Physicians who were listed as Fellows were sent letters about the study and we followed up with telephone calls to arrange participation. Of 427 asked to participate, 118 agreed, representing a 28% response rate. Physicians or office staff then asked patients meeting ACR criteria (5) for FM if they were interested in the study. Patients completed cards indicating their interest and the physician's office staff returned the cards to the University in pre-stamped envelopes. 324 female patients meeting ACR criteria and who had no other chronic health conditions were referred. University staff contacted these patients by telephone and 287 or 89% agreed to participate. Participants were interviewed by phone at baseline and completed four follow-up interviews. Participants were paid $25 for each interview. The final sample for this analysis consisted of 241 participants (84% of the original sample) who had at least two observations used to calculate slopes. Although multi-level modeling techniques are well suited for analysis on data with only one observation when too many people have too few observations, estimation problems arise (34). Consequently, 46 participants (16% of the original sample) who had only one observation of data were excluded leaving 241 participants who had at least two interviews for the analyses. 211 participants or 74% completed all 5 interviews.

This study was approved by the University of Connecticut Health Center Institutional Review Board.

Measures

The study included four measures of health status that assessed the major symptoms of FM, employment status, disease duration and sociodemographic characteristics.

Health Status

Data on health status measures included pain, fatigue, functional status and depressive symptoms. Pain on the day of the interview and fatigue in the past week both were measured on analogue scales Participants were asked, "on a scale of 0–100, with 0 being no pain at all and 100 being the most pain possible, how much pain do you feel today ?" Fatigue was measured by asking participants, "For the following question, indicate on a scale from 0–100 how you have been feeling in the past week. To what degree have you experienced fatigue, from 0 not at all to 100 a great deal." The Modified Health Assessment Questionnaire (MHAQ) (31) assessed functional status. The scale consists of 8 items assessing difficulty, satisfaction and change in 6 months; 0–3 with higher scores indicating worse function. The Center for Epidemiologic Studies Depression Scale (CESD) is a 20 item scale assessing frequency of depressive symptoms (32). Scale scores vary from 0–60 with higher scores indicative of more

depressive symptoms. Mean community scores are about 9 and 16 is considered indicative of clinical depression.

Disease Duration

Disease duration was reported by the participant as number of years since diagnosis.

Sociodemographic characteristics

Sociodemographic characteristics included age measured in years; education, measured in years completed; family income grouped into three categories: <$30,000; $30–49,999; $50,000 +; race as white and non-white; marital status defined as married and not married.

Employment Status

Employment was measured by one self-report item– are you employed for pay outside the home?

Assessment of Time

Changes over time are the critical outcomes being assessed in these growth models. Each interview was scheduled to take place approximately at the one year anniversary date of the previous interview. In order to more precisely evaluate the effects of time, as individuals might vary on the time between interviews, the time between interviews was calculated for each individual time point by the number of days between interviews.

Analysis

Data were analyzed using full maximum-likelihood in SAS PROC MIXED. Time was measured as actual amount of time elapsed between interviews. Multi-level modeling can, not only handle unstructured time, but it can also produce more precise estimated growth rates, as well as, reduce the estimated variance components (33). Demographic variables and disease duration which were used as control variables in the modeling were centered around their grand mean in order to aid in final model interpretation. The employment status variable was left un-centered in order to interpret the effects of those who were employed and those who were not.

Modeling

The approach to the modeling strategy was to first assess the unconditional growth models estimating unadjusted rates of change in the health status measures. We then investigated conditional growth models that looked at the fixed effects of baseline employment status on health status measures over time adjusting for demographic characteristics and disease duration. Each control variable was entered into the model along with its interaction with time. If the interaction was a trend ($p<0.10$), both the main effect and the interaction were retained in the model. If the interaction was not significant ($p >0.10$), the interaction term was removed from the model and the main effect was examined for significance level. If the main effect was non-significant, the variable was removed from the model. Once all the terms that were significant or trending towards significance were examined, we determined whether the variables trending towards significance were confounders. In order to be considered a confounder in the model, the effect of the employment status estimate must have changed >20% and changed in significance. If these criteria were met, the variable was retained in the final model. Finally, the deviance statistic between the final model and the conditional growth model with the employment status variable were compared with a Chi-square test to determine if the model adjusting for the covariates was a better model fit.

Boot strapping methodology adjusted for the cluster sampling design of selecting patients within physician practices.

Results

Description of the sample

There was a good retention rate with 241 participants or 84% completing at least two interviews and 211 participants or 74% completing all five interviews. The only significant difference between those who remained in the study and those who dropped out was that drop-outs were more likely to be non-White. Table 1 shows the demographic characteristics of the sample at the first interview: women were an average of 47 years old, most were married, white and had more than a high school education. The sample was fairly affluent with 40% reporting a family income of over $50,000. About half were employed outside the home for pay.

The average disease duration was 4.9 years, although 13% of the participants had been diagnosed for less than one year. Participants reported high levels of symptoms. The average pain score was 57.2 (sd=24.2) on a scale of 0–100. Fatigue was quite high at a mean of 75 (sd=21.8) and the distribution of scores was skewed toward the high end of the scale. Participants had high levels of functional disability measured by the MHAQ with a mean score of 0.73 (sd=0.46) similar to women with rheumatoid arthritis. Finally, participants had high CESD scores far exceeding the score of 16 indicative of clinical depression with a mean of 22.9 (sd=13.4). A score of 22 is about that of people hospitalized for depression.

Unconditional Growth Models - Changes in Health Status over Time

Slopes were generated with mixed model methods to estimate the unadjusted rate of change over the observation period. Pain did not change significantly over time (slope =−0.299). There was significant improvement in fatigue (slope = −1.02; $p<0.01$), MHAQ (slope = −0.027; $p<0.001$) and depressive symptoms (slope = −0.52; $p<0.01$). These slopes can be interpreted in the following way: for approximately each year of observation, fatigue decreased by 1.02 points; MHAQ decreased by 0.027 points and CESD improved by 0.52 points. Although these are relatively small incremental changes, they are highly significant and could be clinically meaningful. A 2.08 point decline in CESD and 1.08 average decline in MHAQ could be important improvements in health status for these participants (Figure 1).

Multivariate Modeling

Diagnostics—Before conducting multivariate modeling, the data were examined for within-person correlations over time, linearity and distribution of the dependent measures to assess the need for transformation. Random effects for time were included in the CESD and MHAQ models but not in the pain and fatigue models. Covariance parameters for the random effect of time were zero and non-significant and, consequently, were excluded from further models with these measures. In addition, the deviance statistics from the model with the random effect for time and the model without were compared with a Chi-square test with two degrees of freedom. The test suggested that a model without random effects was a better fit for both the pain and fatigue models. The year 1 correlations with subsequent years among each health status measures are presented in Table 2. Correlations are significant and strong across the time points, as well as, demonstrate a decreasing magnitude across the time points, suggesting that alternative covariance structures should be examined. Consequently, the final models were tested with alternative covariance structures: unstructured, compound symmetry, heterogeneous compound symmetry, autoregressive, heterogeneous autoregressive and Toeplitz. None of the covariance structures added substantially to the fit of the model so the standard covariance structure was maintained and used for the final models.

Individual plots of measures over time were visually inspected to identify the shape of the data. Linear trends were suspected but additional tests of models were conducted with quadratic and

cubic terms for time. In all models, these terms were not significant and were dropped from the model.

In both CESD and pain, all time points were skewed, as well as, differences between time points. Normality assumptions for the multi-level models were met once the square root transformation for the CESD measure and the Log10 transformation for pain were created.

Table 3 presents the final results of the HLM analyses for pain (using log transformation), fatigue, MHAQ and the CESD (square root transformation). The first row of the table presents the intercept for each health status measure. Because of the techniques we used, the intercept can be interpreted as the average score on each measure at baseline adjusting for the sociodemographic characteristics. The second row shows the fixed effects of employment status at the initial observation. Employed women had significantly lower fatigue and MHAQ scores compared to women who were not employed. Thus, employed women had, on average, a fatigue score seven points lower than those who were not employed. Likewise, for MHAQ, women who were employed had scores, on average, that were 0.21 points lower than those who were not employed. The effects of employment on the CESD were significant prior to adjusting for the cluster sampling, but the effects were reduced to a trend ($p<0.10$) in the final analyses.

Age and income also were significantly related to health status. Younger women tended to report higher levels of pain, fatigue and depressive symptoms. Women in the highest income groups had lower pain, fatigue, MHAQ and CESD scores compared to those in the middle income group.

The second half of Table 3 presents the results related to changes in health status over time. The row labeled Intercept indicates the rate of change in each health status measure adjusting for the fixed effects and other interaction effects. Pain did not change significantly over time. The other three measures improved significantly over time as shown by the significant negative intercepts. On average, fatigue declined 1.22 (SE=0.61) points, MHAQ decline 0.03 (SE=0.01) points and CESD declined 0.49 (SE=0.9) points per year

There were no significant time-by-employment interactions indicating that employed women had better health status at the start of the study and maintained that advantage over five years. However, there were several significant time interactions with other covariates, including disease duration, age and race. Those with the longest duration of disease tended to experience increasing pain while those having been diagnosed more recently tend to have declining pain. A similar pattern existed for CESD, time and disease duration. Those with the longest duration of disease tended to experience increasing depressive symptoms while those having been diagnosed more recently tend to have declining levels of depression. Younger women tended ($p<0.10$) to have declining fatigue while older women tended to have increasing fatigue. Non-white women reported increasing levels of fatigue and depressive symptoms while white women tended to have decreasing levels of fatigue and depressive symptoms.

The final sections of Table 3 present the results on the variance components, and goodness of fit statistics. The level 2 statistics on initial status, rate of change and covariance provide information on the slopes and intercepts for each measure. Analysis of the rate of change and the covariance components shows that for pain and fatigue there are no random slopes identified. This indicates that the women in this study all have common trajectory over time and no significant random effects associated with within-person variation. In contrast, for MHAQ and CESD, slopes did vary randomly indicating that each woman had a unique experience over time for these health status measures. Furthermore, the covariance measure demonstrates that the slopes not only varied randomly, but that the slope varied as a function

of the initial scores. Where women started out at the baseline measure influenced the trajectory of their disease course.

Discussion

Studies of fibromyalgia patients agree that fibromyalgia patients experience major psychosocial impacts associated with their condition. These studies have reported varying results on the prognosis of fibromyalgia in terms of the major impacts of the disease - pain, fatigue, depressive symptoms and functional status. The results of our study indicate that women with fibromyalgia in this sample improve on fatigue, MHAQ and the CESD over the observation period. Although these improvements are relatively small, they could be clinically meaningful, particularly for MHAQ which demonstrated a 4% reduction in disability per year. Pain did not change significantly.

A major factor that has been shown to provide a protective health benefit over time among women in community studies has been employment. Studies in the general literature on women's health show that employed women are not only healthier, but their health status declines more slowly compared to women who are not employed. A goal of this study was to assess whether women with fibromyalgia experienced the same health advantages. As is found in most studies of women and health status, women in this study who were employed at the baseline interview reported better health status and continued to maintain that advantage over the observation period. There was no interaction between employment and time on the health outcomes studied, indicating that employment did not provide a health advantage to women with fibromyalgia over time. Although women did not experience a health advantage from employment, employed women also did not experience worse health outcomes and managed to maintain better health status over time. This finding suggests that women with fibromyalgia can remain employed with no negative consequences to their condition and probably should try to remain in the labor force as a strategy to maintain better health.

Several demographic characteristics affected the both the initial status of the health status measures as well as disease trajectories. A negative coefficient indicated that younger women reported higher pain, fatigue and CESD scores. This finding was surprising as we would expect younger women to be healthier. This may signify better adjustment to fibromyalgia among older women. Income also was negatively associated with all health status measures. This finding reflects the advantage of higher socioeconomic status among these women.

Disease duration and race/ethnicity significantly influenced disease trajectories as shown by the interaction of this variable with time for CESD and pain. Those with shortest duration had the greatest improvement. This finding may illustrate a natural disease process where some women improve over the short term and their condition resolves while other women experience intractable disease.

In this study non-white women reported increasing levels of fatigue and depressive symptoms while white women tended to have decreasing levels of fatigue and depressive symptoms. These effects are independent of socioeconomic status which was controlled for by family income. Many studies have demonstrated the existence of health disparities among racial and ethnic minority groups in the United States (34) across a broad spectrum of diseases and well as in health care access and in receiving quality health care. A recent review of patients with rheumatic diseases (35) cited several studies that demonstrated health disparities for these conditions. African Americans had higher standardized death rates from arthritis and other rheumatic conditions in the United States from 1979–98. African Americans also have higher prevalence of osteoarthritis but have fewer joint arthroplasties compared to whites. Thus, it is not surprising that this study found that being non-white was associated with worse health

outcomes measured by worse depression scores and greater fatigue compared to being white. The number of non-whites in our sample was relatively small, about 10% of participants, but the impacts of race/ethnicity must be fairly large to reach statistical significance. We investigated several potential mediating factors, including socioeconomic status, social support and family factors, but these variables did not explain differences in these health outcomes. As other investigators in the area of health disparities suggest, the underlying psychosocial and biological factors contributing to these disparities should be investigated further.

An interesting finding was that there were no random effects demonstrated for the major symptoms of FM - pain and fatigue. This finding suggests that the participants experienced similar patterns of pain and fatigue over time that could be related to an underlying biomedical mechanism of FM that is common across women with this condition. In contrast, the *impacts* of the disease, disability and depression, do vary individually among women over time. The relationships between symptoms and outcomes and factors that mediate outcomes should be investigated.

A strength of this study is that it is a national sample drawn from rheumatology practices. However, there are several limitations as well. Because of the nature of the sample, the results are not generalizable beyond women being treated in rheumatology practices. There could be selection bias in that women with more serious disease or worse symptoms volunteered for the study. Women had fibromyalgia for varying lengths of time and this study only provides a brief snapshot of the experiences of these women. As shown by our results on disease duration, this factor should be taken into consideration in future studies. Recently diagnosed patients may have very difference experiences than those with long-term disease. Finally, non-white women had very different experiences of fibromyalgia compared to white women. Our sample included a relatively small number of non-white women. This finding is suggestive, but should be viewed cautiously. The effects of race and ethnicity should be investigated further.

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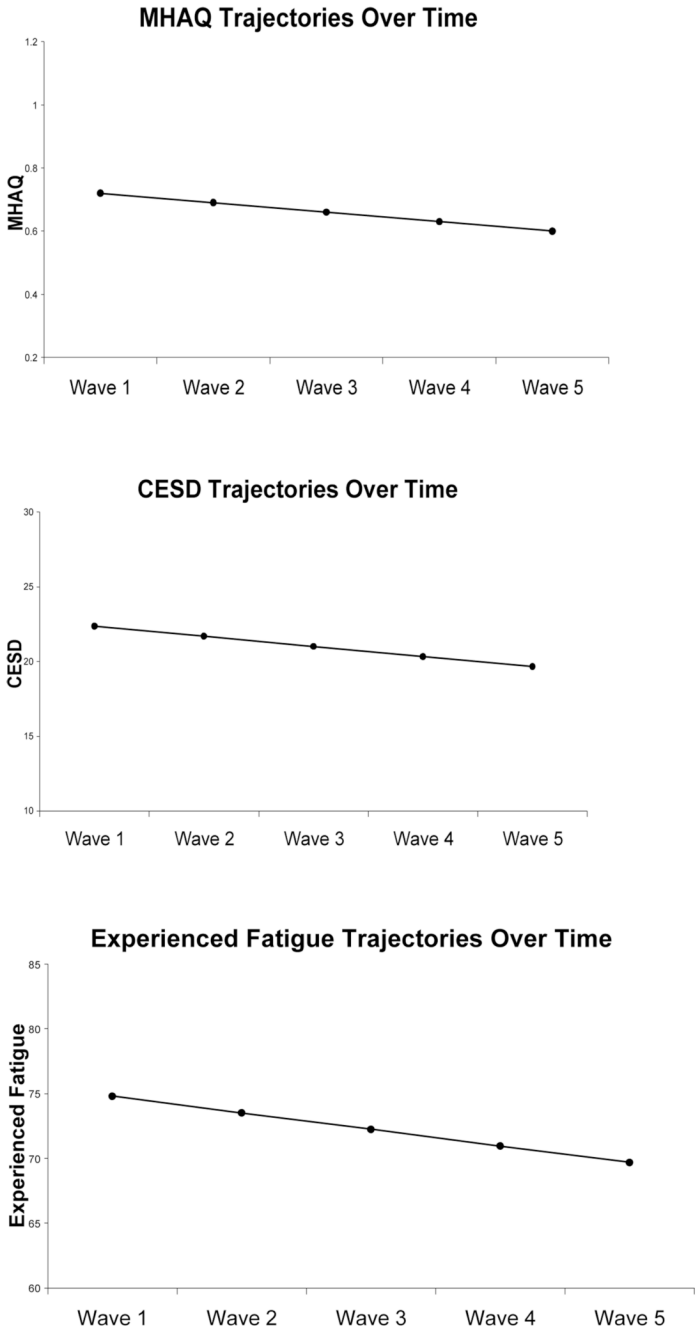

Figure 1.
Trajectories of MHAQ, CESD and Fatigue over Time

Table 1

Baseline demographic characteristics of participants (n=241)

Variables	FM Participants (n = 241)
Age, yrs, mean (SD),	47 (10.8)
% Married	63.5
% Non-Hispanic White	90.5
Education, mean (SD), yrs	14 (2.5)
Income	
%<$30,000	29.9
%$30–49,999 (referent)	29.9
%$50,000 +	40.2
% Currently Employed	50.2
Disease Duration, mean (SD, yrs	4.9 (4.4)
Pain Today, mean (SD)	57.2 (24.2)
Experienced Fatigue, mean (SD)	75.4 (21.8)
MHAQ, mean (SD)	0.73 (0.46)
CESD, mean (SD)	22.9 (13.4)

Table 2

Means (SD) for Pain, MHAQ, CESD and Fatigue in Year 1 and Pearson Correlations between Measures in Year 1 and Years 2–5.

Year	Mean (sd) Pain Today	r	Mean (sd) MHAQ	r	Mean (sd) CESD	r	Mean (sd) Fatigue	r
1	57.2 (24.20)	--	0.73 (0.46)	--	22.9 (13.44)	--	75.4 (21.75)	--
2	55.3 (25.32)	.39	0.67 (0.43)	.68	21.2 (12.95)	.67	71.7 (23.71)	.48
3	56.1 (24.39)	.42	0.68 (0.47)	.71	20.8 (12.71)	.65	74.4 (22.94)	.40
4	54.4 (24.33)	.33	0.64 (0.44)	.66	21.5 (13.19)	.62	72.5 (23.33)	.54
5	56.6 (26.24)	.39	0.61 (0.43)	.55	20.5 (12.78)	.57	70.3 (23.71)	.40

Table 3

Final Results of the HLM Analyses for Pain (using log transformation), Fatigue, MHAQ and the CESD (square root transformation)

			Pain[1]	Fatigue	MHAQ	CESD[2]
Fixed Effects						
Initial Status, π_{0i}	Intercept	γ_{00}	1.72*** (0.03)	81.5 (1.9)***	0.81 (0.04)***	4.83 (0.2)***
	Employment	γ_{01}	−0.02 (0.04)	−7.05 (2.15)***	−0.21 (0.05)***	−0.34 (0.18)+
	Education	γ_{02}	−0.01 (0.01)+			
	Age	γ_{04}	−0.005 (.001)*	0.52 (0.14)***		−0.03 (0.01)**
	Income <$30,000	γ_{05}	0.03 (0.05)	2.05 (2.39)	0.06 (0.06)	0.21 (0.19)
	>=$50,000	γ_{06}	−0.08 (0.04)*	−9.58 (2.79)**	−0.17 (0.05)**	−0.61 (0.22)**
	Non-White	γ_{08}			0.18 (0.10)+	
Rate of Change, π_{2i}	Intercept	γ_{10}	−0.01 (0.01)	−1.57 (0.61)*	−0.03 (0.01)***	−0.09 (0.03)**
	Employment	γ_{11}	NS	NS	NS	NS
	Disease Dur	γ_{13}	0.02 (0.01)*	NS	0.01 (0.01)+	0.06 (0.02)*
	Age	γ_{14}		0.10 (0.05)+		
	Non-White	γ_{18}		3.66 (1.62)*		0.18 (0.09)*
Variance Component						
Level 1	Within Person	$\sigma^2\varepsilon$	0.08 (0.004)***	297.2 (13.2)***	0.06 (0.00)***	0.762 (0.04)***
Level 2	Initial Status	σ^2_0	0.04 (0.006)***	192.8 (23.66)***	0.12 (0.02)***	1.37 (0.17)***
	Rate of Change	σ^2_1	*3*	*3*	0.00[5] (0.00)**	0.052 (0.02)**
	Covariance	σ^2_{01}	*4*	*4*	−0.01 (0.00)	−0.09 (0.04)*

[1] Pain measure transformed using Log10

[2] CESD transformed using square root.

[3] Variance components for rate of change were not estimated when the model did not include the random effect

[4] Covariance between initial status and rate of change were not calculated because the random effect for rate of change was excluded.

[5] Due to rounding, values look like 0.

+ p<0.10

* p<0.05

** p<0.01

*** p<0.001