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PREDICTORS OF NON-RESPONSE AND NON-COMPLIANCE IN AFRICAN AMERICAN LUPUS PATIENTS: FINDINGS FROM THE BALANCING LUPUS EXPERIENCES WITH STRESS STRATEGIES (BLESS) STUDY

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Abstract

Arthritis self-management education has demonstrated significant improvements in health distress, self-reported global health, and activity limitation, with trends toward improvement in self efficacy and mental stress management. Consequently, numerous national agencies have recommended arthritis self-management education to complement medical care. Despite these recommendations, arthritis self-management education has reached only a limited number of people. Compliance is also a persistent problem in standardized programs. As part of the Balancing Lupus Experiences with Stress Strategies (BLESS) Study, a validated psychosocial stress intervention was piloted among a cohort of African American lupus patients participating in an SLE database project at the Medical University of South Carolina (MUSC). Recruitment attempts were made with the 330 database participants who met eligibility requirements for the study. While enrollment was limited to 30 participants (n=15 controls and n=15 intervention), two of the participants assigned to the intervention group did not attend any intervention sessions and several participants did not complete post-intervention questionnaires. Therefore, data were analyzed on 30 participants at baseline, 25 (n=13 controls and n=12 intervention) at post-intervention, and 22 (n=12 controls and n=10 intervention) at four months post-intervention. In an effort to characterize those who fully participated in the study and those who were non-compliant or non-responsive to recruitment attempts, we obtained descriptive data from African-American Lupus patients participating in the SLE Clinic Database Project. This information can be used to develop and refine future intervention activities..

INTRODUCTION

Lupus Disease Experience of African Americans

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease with acute periodic flare-ups of symptoms impacting any organ system and resulting in potentially life-threatening complications. (Rahman and Isenberg 2008; Pons-Estel et al. 2010) A number of studies have shown that African-Americans are at increased risk for morbidity and mortality from SLE(Siegel and Lee 1973; Michet et al. 1985; McCarty et al. 1995; Alarcón et al. 1998; Cooper et al. 2002). In these studies, SLE occurrence was three to four times higher among African-American than Caucasian white women, and high levels of disease activity are more commonly observed in African-Americans(Alarcón et al. 1998). Other significant complications of treatment include hirsutism, weight gain, osteoporosis, osteonecrosis, accelerated atherosclerosis, and retinal damage.(Wallace 2000; Roman et al. 2003; Rahman and Isenberg 2008; Pons-Estel et al. 2010) These side effects and complications can lead to significant functional and emotional challenges. Patients often experience a high degree of psychological symptoms, including anxiety, depression, mood disorders, and decreased health-related quality of life.(Dobkin et al. 1998; Seawell and Danoff-Burg 2004; Bachen et al. 2009; Danoff-Burg and Friedberg 2009; Kulczycka et al. 2010; Jarpa et al. 2011)

In addition to managing disease-specific stressors, it has been suggested that African-Americans are exposed to a unique set of risk factors that lead to a pattern of cumulative disadvantage over time. High rates of unemployment, poverty, violent crime, incarceration, and homicide among African-American adults reflect this accumulation of disadvantage at multiple transition points during their development and across the life course. (Hertzman and Wiens 1996; Carroll 1998; Cattell 2001; Williams 2001; Dobkin, Da Costa et al. 2002; Williams 2003; Wyatt et al. 2003; Greco et al. 2004; O'Donnell 2004; Bijlani et al. 2005; Coalition 2005; Lorig et al. 2005; Gaab et al. 2006) It is highly likely that early childhood exposure to segregated, economically impoverished neighborhoods created by institutionalized racism adversely affects child health and growth and sets the Black child on a low education and economic trajectory that increases the risk of poor physical and mental health in adulthood.(Hertzman and Wiens 1996) Additional stressors include deprivation of resources and facilities, differential exposure to health risks in the physical environment because of economically disadvantaged neighborhoods and poor quality housing, higher costs of goods and services in deprived areas, as well as roles of social networks and social capital, which often give rise to peer pressure against academic achievement and in support of crime and substance use.(Cattell 2001; Williams 2001; Williams 2003; Wyatt et al. 2003) Due to the exposure of African-Americans to a unique trajectory of stressors throughout the life course, it may be critical to address modifiable risk factors for SLE that may be further exacerbated by this trend in an effort to improve health status and reduce health disparities in this high risk group.

Evidence Based Prevention Programs

A large body of evidence has shown that health-promoting programs in stress management have been successful in helping people improve their health practices and related health conditions.(O'Donnell 2004) Such techniques have also resulted in short-term improvement in pain, fatigue, psychological function, and perceived physical function among persons with SLE (Karlson, Liang et al. 2004). Although there is no generally accepted self-management program available for SLE(Danoff-Burg and Friedberg 2009), two programs that have been shown to be successful in improving conditions in patients with arthritis are the Arthritis Self-Management Program (ASMP) and the generic Chronic Disease Self-Management Program (CDSMP). Each program incorporates six weeks of peer led sessions ranging in disease-specific and more general self-help content. Both programs have demonstrated significant improvements in health distress, self-reported global health, and activity limitation, with trends toward improvement in self efficacy and mental stress management. (Lorig et al. 1985; Lorig and Holman 1993; Lorig et al. 1993; Kruger et al. 1998; Barlow et al. 2000; Brady et al. 2003; Lorig et al. 2005) Consequently, numerous national agencies have recommended arthritis self-management education to complement medical care. Despite these recommendations, arthritis self-management education has reached only a limited number of people.

Barriers to Participation

A number of potential predictors of poor compliance and appointment-keeping behavior have been identified(Fiester and Rudestam 1975; Dove and Schneider 1981; Goldman et al. 1982; Frankel et al. 1989; Melnikow and Kiefe 1994), and there are numerous potential barriers to adherence.

Noncompliance with treatment has been associated with worse outcome in numerous clinical disorders (Jones et al. 1990; McDermott et al. 1997; Dyer et al. 1998). For example, Petri et al (1992) found that African American patients with SLE had poorer renal outcomes than white patients, and this difference was related to increased hypertension and poorer treatment adherence among the African American patients.(Petri et al. 1992)

Despite the apparent need for help with multiple illness-related problems and evidence that some of these problems can be ameliorated with cognitive-behavioral interventions without adverse effect, several studies have emphasized the need to design interventions that address barriers to participation and curtail noncompliance(Mirotznik et al. 1998; Gladman et al. 2000; Mosley-Williams, Lumley et al. 2002; Uribe et al. 2004), particularly for African-American patients. Practicing physicians continue to struggle with patient compliance, poor adherence to therapeutic regimens, and failure of patients to keep scheduled appointments. For example, Petri et al (1991) found that physicians rated African-Americans as less globally adherent than whites (43.5% versus 66.3% adherent, respectively). (Petri et al. 1992)

The BLESS Study

The Balancing Lupus Experiences with Stress Strategies (BLESS) intervention piloted a validated stress management program and incorporated valid measures of psychosocial and neuroendocrine responses to stress to assess its effectiveness in reducing perceived and biological indicators of stress in 30 African-American lupus patients participating in the SLE Clinic Database Project at the Medical University of South Carolina (MUSC). This was achieved through 6 weekly, group sessions (N=15) of the “Better Choices, Better Health” Chronic Disease Self-Management Program (CDSMP). Patients randomly assigned to the control condition received general disease information and relevant literature. Overall, patients who received the intervention reported improved self-efficacy pertaining to coping with having lupus, less health distress, post intervention, and lower levels of depression, compared with controls. All measures of quality of life were significantly different between groups, with the exception of ‘communication with physician’. We observed large effects upon depression (d=1.63), social/role activities limitations (d=1.15), health distress (d=1.13), fatigue (d=1.03), pain (d=0.96), and lupus self-efficacy (d=0.85), and concluded that the intervention workshops acted to reduce perceived stress and improve quality of life(Williams, Kamen et al. 2014; Williams, Penfield et al. 2014).

The current study sought to explore predictors of non-compliance and non-response in an African American study population, with the hypothesis that areas of commonality would emerge for non-compliant and non-responsive patients when compared with the population targeted for recruitment. For the purposes of this study, we considered a participant non-compliant if they agreed to participate in the study and then missed 3 or more of the six weekly CDSMP sessions and/or did not complete assessment tools. All patients targeted for recruitment who did not respond to recruitment efforts were considered non-responsive. Descriptive data from African-American Lupus patients participating in the MUSC SLE Clinic Database Project was obtained to characterize those who fully participated in the study and those who were non-compliant or non-responsive to recruitment attempts, in hopes that this information can be used to develop and refine future intervention activities and improve such trends.

METHODS

Patients invited to participate in the BLESS study were African American SLE patients attending rheumatology clinics at MUSC. All SLE patients met at least four components of the 1997 ACR revised criteria for SLE(Hochberg 1997), were 18 years of age or older, and had not previously participated in a self management program. The total number of individual patients with SLE, currently being followed by clinicians at MUSC, averages 1,265 annually within the past 3 years. The total number of new patients with SLE seen in the past year by clinicians at MUSC was 176, of which 61% were African-American and 88% were female. Patients invited to participate in the proposed study are lupus patients participating in a longitudinal observational web-based SLE Database at MUSC. There are 402 patients with lupus currently enrolled, and these patients are seen on a regular basis in the MUSC lupus clinics. All patients have American College of Rheumatology (ACR) criteria and disease activity information available, as well as quality of life measures obtained in the database questionnaire. The database is web-based, allowing quick identification of potential participants in clinical trials since, as part of the informed consent process, participants agree to future re-contact regarding other research studies. MUSC's SLE cohort is geographically diverse, representing more than 60 South Carolina and North Carolina counties. Of the 402 patients with lupus, 336 are African-American, and 218 of the 336 are Gullah African-American from the Sea Islands of South Carolina and Georgia. Additionally, as part of the associated SLE in Gullah Health (SLEIGH), 166 unrelated age- and gender-matched Gullah controls and 216 family-member Gullah controls are enrolled.

Eligible patients were invited to participate by a mailed letter that described the study and in person, during regular clinic visits. Interested patients were randomly assigned to the intervention or usual medical care alone. Prior to study participation, subjects completed informed consent documents approved by the University of South Carolina (USC) and Medical University of South Carolina (MUSC) Institutional Review Boards. Recruitment attempts were made with the 330 database participants who met eligibility requirements for the study. While enrollment was limited to 30 participants (n=15 controls and n=15 intervention), two of the participants assigned to the intervention group did not attend any intervention sessions and several participants did not complete post-intervention questionnaires. Therefore, data were analyzed on 30 participants at baseline, 25 (n=13 controls and n=12 intervention) at post-intervention, and 22 (n=12 controls and n=10 intervention) at four months post-intervention.

All statistical analyses were conducted using SAS 9.2 (SAS Institute, Cary, North Carolina). For categorical variables, the number and percent of each variable in each study group were calculated with p values from Chi-square or Fisher's exact t tests. For continuous variables, the mean, standard deviation, median and range (minimum and maximum) were calculated with p values from the two-sample t or Mann Whitney U tests. For multiple choice questions, which means one could choose more than one answer, the number and percent of each choice in each study group was calculated with p values from the large-sample Z test for proportions. For time to the onset of disease, basic summary statistics of continuous variables were obtained with the p-value from the cumulative distribution function (cdf) to indicate the time to onset of disease for participants in each group. Time in years was calculated as: Year (disease) – Year (birth) + 1. For the variable time, the mean, standard deviation, median and range (minimum, maximum) are reported as well as a p value from the cdf. Those reflected in the analysis are limited to those who displayed the disease manifestation by the time they were recruited for the BLESS study.

RESULTS

Tables 1 and 2 present patient background information, including gender, age, insurance status, highest year of education completed, and current and past employment status, for all patients and randomized BLESS Study participants. Insurance and past and current employment status were multiple choice questions. In addition to analysis for each choice, these variables were also investigated categorically according to whether a subject had insurance or not and whether the subject was working or not. The background information presented in Table 1, was compared between 303 non-respondents and 30 respondents who participated in the BLESS Study. The P-values regarding for gender, age, highest year of education and overall test for insurance and employment status were not significant, with the smallest value being 0.45. These results suggest that there was no difference between non-respondents and BLESS study participants with respect to background information, which suggests that the sample was representative of the study population BLESS participants were recruited from. There were significant p values observed in some

Table 1: Background Information (All**)**

	Non-respondants	**BLESS Patients**	**P value**
	N=303	N=30	
Gender			
			1.000
Female	281(92.74%)	28(93.33%)	
Male	22(7.26%)	2(6.67%)	
			0.811
Age			
Mean	38.27	37.51	
Standard Deviation	12.88	12.11	
Median	38.09	35.64	
Range(Min~Max)	67(11~78)	42(18~60)	
			0.464
Insurance			
Uninsured	90(29.70%)	7(23.33%)	
Insured	213(70.30%)	23(76.67%)	
Private	105(34.7%)	9(30.0%)	0.86
Medicaid	89(29.4%)	12(40.0%)	0.142
Medicare	77(25.4%)	9(30.0%)	0.415
Uninsured	24(7.9%)	1(3.3%)	0.277
Unknown	2(0.7%)	0(0.0%)	<.001*
			0.824
Current Employment Status			
Out of work	208(68.65%)	20(66.67%)	
Working	95(31.35%)	10(33.33%)	
Under working age	1(0.3%)	0(0.0%)	<.001*
Working	95(31.4%)	10(33.3%)	0.575
Retired	15(5.0%)	1(3.3%)	0.736
Homemaker	8(2.6%)	0(0.0%)	<.001*
Student	29(9.6%)	3(10.0%)	0.817
Disabled	100(33.0%)	12(40.0%)	0.264
Unemployed	27(8.9%)	5(16.7%)	0.214
			0.514
Past Employment Status			
Out of work	109(35.97%)	9(30.00%)	
Working	194(64.03%)	21(70.00%)	
Under working age	3(1.0%)	1(3.3%)	0.435
Working	194(64.0%)	21(70.0%)	0.109
Retired	1(0.3%)	0(0.0%)	<.001*
Homemaker	5(1.7%)	0(0.0%)	<.001*
Student	31(10.2%)	3(10.0%)	0.901
Disabled	29(9.6%)	3(10.0%)	0.822
Unemployed	4(1.3%)	1(3.3%)	0.507
			0.45
Highest year of education completed			
<=Grade School	6(2.0%)	0(0.0%)	
High School	118(38.9%)	8(26.7%)	
College	78(25.7%)	8(26.7%)	
>College	48(15.8%)	8(26.7%)	
Unknown/Missing	53(17.5%)	6(20.0%)	

of the choices of insurance and employment status, but due to the small sample sizes in respective subgroups, they cannot be interpreted as indicators of significant differences. For example, in current employment status, the choice 'under working age' had a p value <.001, but only one of 303 non-respondents and no BLESS participants chose this answer. For BLESS Study participants shown in Table 2, background information is compared between 15 intervention group participants and 15 controls. Similar to Table 1, no significant differences were observed in the background information between the intervention and control groups, suggesting that the two study groups were comparable at baseline.

Tables 3 and 4 present disease history for all patients and randomized BLESS Study participants. Disease factors considered include malar rash, discoid rash, photosensitivity, oral/nasal ulcers, arthritis, serositis, renal disorder, neuro disorder, heme disorder, immune disorder, and ANA positivity. For all patients in Table 3, disease history variables were compared between 303

Table 2: Background Information (Randomised)

	Intervention	**Control**	**P value**
	N=15	N=15	
Gender			1.000
Female	14(93.33%)	14(93.33%)	
Male	1(6.67%)	1(6.67%)	
			0.716
Age			
Mean	38.33	36.68	
Standard Deviation	11.09	13.38	
Median	40.77	34.18	
Range(Min~Max)	36(22~58)	42(18~60)	
			1.000
Insurance			
Uninsured	4(26.67%)	3(20.00%)	
Insured	11(73.33%)	12(80.00%)	
Private	4(26.7%)	5(33.3%)	0.679
Medicaid	6(40.0%)	6(40.0%)	1
Medicare	2(13.3%)	7(46.7%)	0.019*
Uninsured	0(0.0%)	1(6.7%)	<.001*
Unknown	0(0.0%)	0(0.0%)	/
			0.245
Current Employment Status			
Out of work	8(53.33%)	12(80.00%)	
Working	7(46.67%)	3(20.00%)	
Under working age	0(0.0%)	0(0.0%)	/
Working	7(46.7%)	3(20.0%)	0.085
Retired	1(6.7%)	0(0.0%)	<.001*
Homemaker	0(0.0%)	0(0.0%)	/
Student	0(0.0%)	3(20.0%)	<.001*
Disabled	5(33.3%)	7(46.7%)	0.426
Unemployed	3(20.0%)	2(13.3%)	0.613
			0.427
Past Employment Status			
Out of work	6(40.00%)	3(20.00%)	
Working	9(60.00%)	12(80.00%)	
Under working age	1(6.7%)	0(0.0%)	<.001*
Working	9(60.0%)	12(80.0%)	0.075
Retired	0(0.0%)	0(0.0%)	/
Homemaker	0(0.0%)	0(0.0%)	/
Student	2(13.3%)	1(6.7%)	0.518
Disabled	3(20.0%)	0(0.0%)	<.001*
Unemployed	1(6.7%)	0(0.0%)	<.001*
			0.104
Highest year of education completed			
<=Grade School	0(0.0%)	0(0.0%)	
High School	1(6.7%)	7(46.7%)	
College	5(33.3%)	3(20.0%)	
>College	5(33.3%)	3(20.0%)	
Unknown/Missing	4(26.7%)	2(13.3%)	

non-respondents and 30 respondents who participated in the BLESS Study. No significant differences were observed between non-respondents and BLESS Study participants, suggesting that non-respondents and BLESS study participants were comparable with respect to disease history, and that the sample was representative of the study population BLESS participants were recruited from. For BLESS Study participants shown in Table 4, disease history was compared between 15 intervention group participants and 15 controls. Similar to Table 3, P values were all larger than 0.05 in disease history between the intervention and control groups, suggesting that the two study groups were comparable.

Tables 5 and 6 present time to the onset of disease for all patients and randomized BLESS Study participants. For all patients in Table 5, time to the onset of disease were compared between 303 non-respondents and 30 respondents who participated in the BLESS Study. Among all of the disease factors, marginal significant

Table 3: Disease History (All)

	Non-respondants	**BLESS Patients**	**P value**
	N=303	N=30	
Malar rash			0.573
Yes	149(49.17%)	13(43.33%)	
No	99(32.67%)	11(36.67%)	
Discoid rash			0.426
Yes	191(63.04%)	17(56.67%)	
No	54(17.82%)	7(23.33%)	
Photosensitivity			0.404
Yes	141(46.53%)	11(36.67%)	
No	107(35.31%)	12(40.00%)	
Oral / Nasal Ulcers			0.169
Yes	178(58.75%)	13(43.33%)	
No	75(24.75%)	10(33.33%)	
Arthritis			0.132
Yes	96(31.68%)	5(16.67%)	
No	160(52.81%)	18(60.00%)	
Serositis			0.400
Yes	170(56.11%)	14(46.67%)	
No	75(24.75%)	9(30.00%)	
Renal disorder			0.728
Yes	153(50.50%)	14(46.67%)	
No	94(31.02%)	10(33.33%)	
Neuro disorder			1.000
Yes	207(68.32%)	21(70.00%)	
No	37(12.21%)	3(10.00%)	
Heme disorder			0.920
Yes	132(43.56%)	13(43.33%)	
No	107(35.31%)	11(36.67%)	
Immune disorder			0.857
Yes	92(30.36%)	9(30.00%)	
No	132(43.56%)	14(46.67%)	
ANA positivity			1.000
Yes	49(16.17%)	4(13.33%)	
No	200(66.01%)	20(66.67%)	

difference were observed in three of them; time to onset of renal disorder (p=0.056) as shown in Figure 1, heme disorder (p=0.055) as shown in Figure 2 and SLE diagnosis (p=0.069) as shown in Figure. Table 5 shows that BLESS Study participants more quickly arrived at these three disease manifestations. For BLESS Study participants shown in Table 6, time to the onset of disease was compared between 15 intervention group participants and 15 controls ,and only heme disorder had a significant p value (p=0.019). We further show the cumulative probability curves for time to the onset of disease manifestations for all patients and randomized BLESS Study participants. Due to missing values in the control group, we didn’t report the cumulative probability for the intervention and control groups, individually. The cumulative probability curves show that the chance that a patient will display disease manifestation is different between non-respondents and BLESS Study participants. BLESS Study participants generally displayed shorter time periods to the onset of various disease factors, when compared with non-respondents.

DISCUSSION

Our study found that respondents (n=30) and non-respondents (n=303) to an intervention program to improve quality of life and reduce indicators of stress in African American lupus patients were generally similar

Table 4: Disease History (Randomised)

	Intervention N=15	Control N=15	P value
Malar rash			0.107
Yes	9(60.00%)	4(26.67%)	
No	4(26.67%)	7(46.67%)	
Discoid rash			0.659
Yes	10(66.67%)	7(46.67%)	
No	3(20.00%)	4(26.67%)	
Photosensitivity			0.414
Yes	5(33.33%)	6(40.00%)	
No	8(53.33%)	4(26.67%)	
Oral / Nasal Ulcers			1.000
Yes	7(46.67%)	6(40.00%)	
No	6(40.00%)	4(26.67%)	
Arthritis			0.339
Yes	4(26.67%)	1(6.67%)	
No	9(60.00%)	9(60.00%)	
Serositis			1.000
Yes	8(53.33%)	6(40.00%)	
No	5(33.33%)	4(26.67%)	
Renal disorder			1.000
Yes	8(53.33%)	6(40.00%)	
No	5(33.33%)	5(33.33%)	
Neuro disorder			1.000
Yes	11(73.33%)	10(66.67%)	
No	2(13.33%)	1(6.67%)	
Heme disorder			0.392
Yes	6(40.00%)	7(46.67%)	
No	7(46.67%)	4(26.67%)	
Immune disorder			1.000
Yes	5(33.33%)	4(26.67%)	
No	7(46.67%)	7(46.67%)	
ANA positivity			0.596
Yes	3(20.00%)	1(6.67%)	
No	10(66.67%)	10(66.67%)	

Table 5: Years Before Onset (All)

	Non-respondants N=303	**BLESS Patients** N=30	**P value**
Malar rash			0.271
N	84	9	
Mean	30.68	26.44	
Standard Deviation	14.44	11.44	
Median	28.5	26	
Range(Min~Max)	67(3~70)	33(11~44)	
Discoid rash			0.398
N	45	6	
Mean	28.22	24.33	
Standard Deviation	13.25	10.39	
Median	27	22	
Range(Min~Max)	54(6~60)	31(12~43)	
Photosensitivity			0.656
N	89	10	
Mean	30.17	30.8	
Standard Deviation	15.99	9.6	
Median	27	27.5	
Range(Min~Max)	66(4~70)	28(20~48)	
Oral / Nasal Ulcers			0.522
N	62	9	
Mean	32.92	30.44	
Standard Deviation	13.15	12.45	

Table 5 Contd

Median	31.5	31	
Range(Min~Max)	68(2~70)	37(11~48)	
Arthritis			0.603
N	130	17	
Mean	30.14	28.71	
Standard Deviation	14.17	13.91	
Median	28	27	
Range(Min~Max)	69(1~70)	44(11~55)	
Serositis			0.265
N	70	7	
Mean	30.41	27.43	
Standard Deviation	13.62	8.08	
Median	29	26	
Range(Min~Max)	61(1~62)	24(18~42)	
Renal disorder		0.056	
N	83	10	
Mean	30.46	23.9	
Standard Deviation	13.68	9.3	
Median	28	24.5	
Range(Min~Max)	57(3~60)	30(11~41)	
Neuro disorder		0.436	
N	33	3	
Mean	26.67	25.33	
Standard Deviation	12.15	5.51	
Median	26	25	
Range(Min~Max)	45(8~53)	11(20~31)	
Heme disorder		0.055	
N	84	10	
Mean	31.06	24.3	
Standard Deviation	13.96	8.14	
Median	29	25	
Range(Min~Max)	61(9~70)	24(11~35)	
Immune disorder		0.153	
N	116	12	
Mean	31.68	27.33	
Standard Deviation	13.42	11.16	
Median	28.5	24.5	
Range(Min~Max)	61(9~70)	33(11~44)	
ANA positivity		0.939	
N	166	17	
Mean	32.58	31.29	
Standard Deviation	13.72	15.33	
Median	33	26	
Range(Min~Max)	69(1~70)	51(11~62)	
SLE diagnosed		0.069	
N	180	18	
Mean	29.63	25.06	
Standard Deviation	14.5	11.14	
Median	28	23	
Range(Min~Max)	69(1~70)	42(6~48)	

with regard to demographic factors and various disease indices. While our results suggest that factors outside of those related to disease and socioeconomic status may be more significant predictors of non-adherence and non-compliance, we did observe some trends that could have implications for the development and implementation of future interventions. Our finding that study participants more quickly arrived at disease manifestations of renal disorder, heme disorder, and SLE diagnosis, when compared with non-respondents to recruitment efforts, suggests that more rapid onset of SLE may be more motivating than a more insidious onset and special efforts may have to be made to recruit those with later onset SLE. Our finding of more rapid onset of heme disorder in study participants also suggest that they were more fatigued at baseline, when compared with non-respondents. This along with the homemaker finding is interesting, as those caring for

Table 6: Years Before Onset (Randomized)

	Intervention N=15	**Control** N=15	**P value**
Malar rash			0.663
N	3	6	
Mean	25	27.17	
Standard Deviation	6.56	13.79	
Median	26	24	
Range(Min~Max)	13(18~31)	33(11~44)	
Discoid rash			0.486
N	3	3	
Mean	20	28.67	
Standard Deviation	7.55	12.5	
Median	21	23	
Range(Min~Max)	15(12~27)	23(20~43)	
Photosensitivity			0.943
N	7	3	
Mean	30.86	30.67	
Standard Deviation	9.67	11.59	
Median	26	29	
Range(Min~Max)	28(20~48)	23(20~43)	
Oral / Nasal Ulcers			0.799
N	6	3	
Mean	32	27.33	
Standard Deviation	9.84	18.88	
Median	32.5	23	
Range(Min~Max)	28(17~45)	37(11~48)	
Arthritis			0.566
N	9	8	
Mean	27.67	29.88	
Standard Deviation	12.77	15.91	
Median	27	25	
Range(Min~Max)	42(11~53)	44(11~55)	
Serositis			0.701
N	5	2	
Mean	27.8	26.5	
Standard Deviation	9.55	4.95	
Median	26	26.5	
Range(Min~Max)	24(18~42)	7(23~30)	
Renal disorder		0.546	
N	5	5	
Mean	26.4	21.4	
Standard Deviation	5.73	12.1	
Median	27	20	
Range(Min~Max)	14(17~31)	30(11~41)	
Neuro disorder		0.808	
N	2	1	
Mean	25.5	25	
Standard Deviation	7.78	.	
Median	25.5	25	
Range(Min~Max)	11(20~31)	0(25~25)	
Heme disorder		0.019*	
N	7	3	
Mean	27.43	17	
Standard Deviation	6.85	6.56	
Median	29	16	
Range(Min~Max)	18(17~35)	13(11~24)	
Immune disorder		0.709	
N	6	6	
Mean	28.33	26.33	
Standard Deviation	8.8	13.94	
Median	28.5	22	
Range(Min~Max)	24(17~41)	33(11~44)	
ANA positivity		0.263	
N	9	8	

Table 6 Contd

Mean	27.89	35.13
Standard Deviation	13.32	17.4
Median	24	36
Range(Min~Max)	43(17~60)	51(11~62)
SLE diagnosed		0.724
N	9	9
Mean	25.67	24.44
Standard Deviation	7.86	14.19
Median	24	22
Range(Min~Max)	23(17~40)	42(6~48)

Figure 1: Time to the onset of Renal disorder (All)

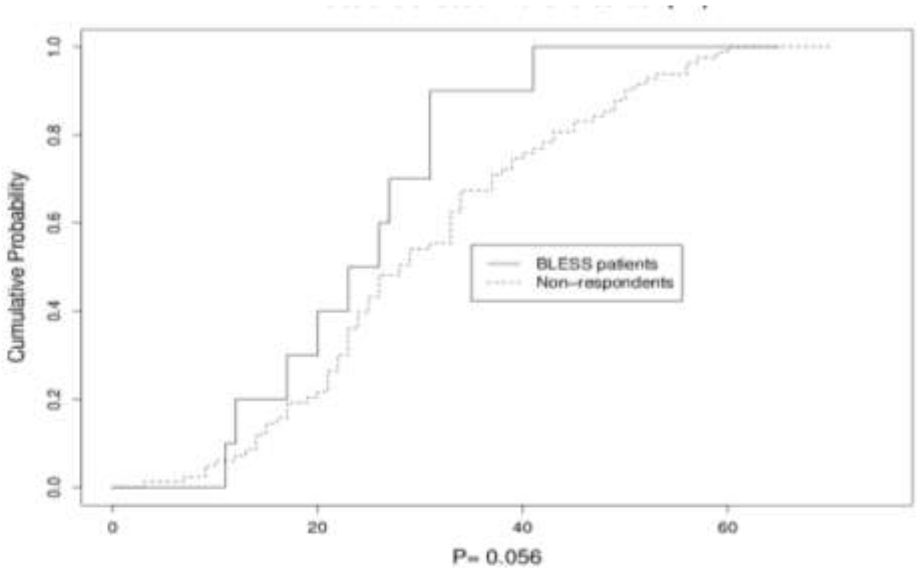


Figure 2: Time to the onset of Heme disorder (All)

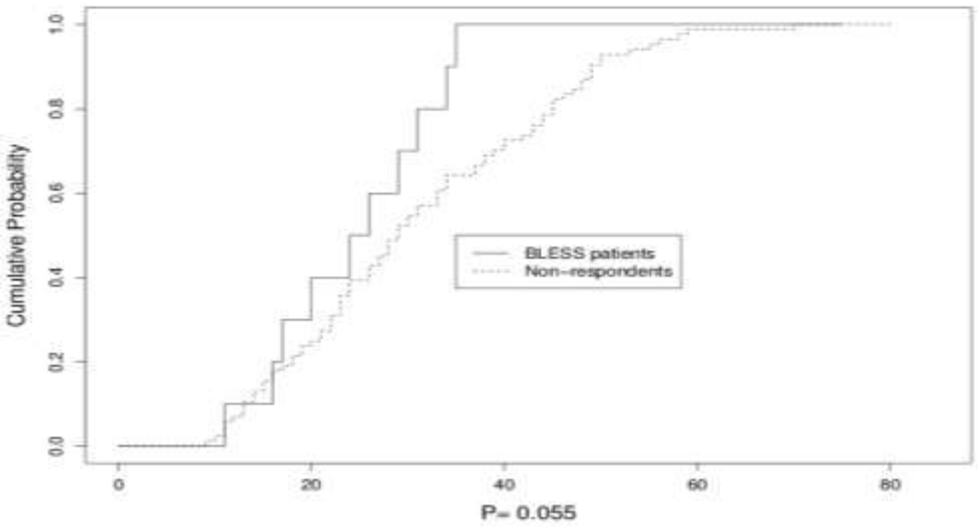
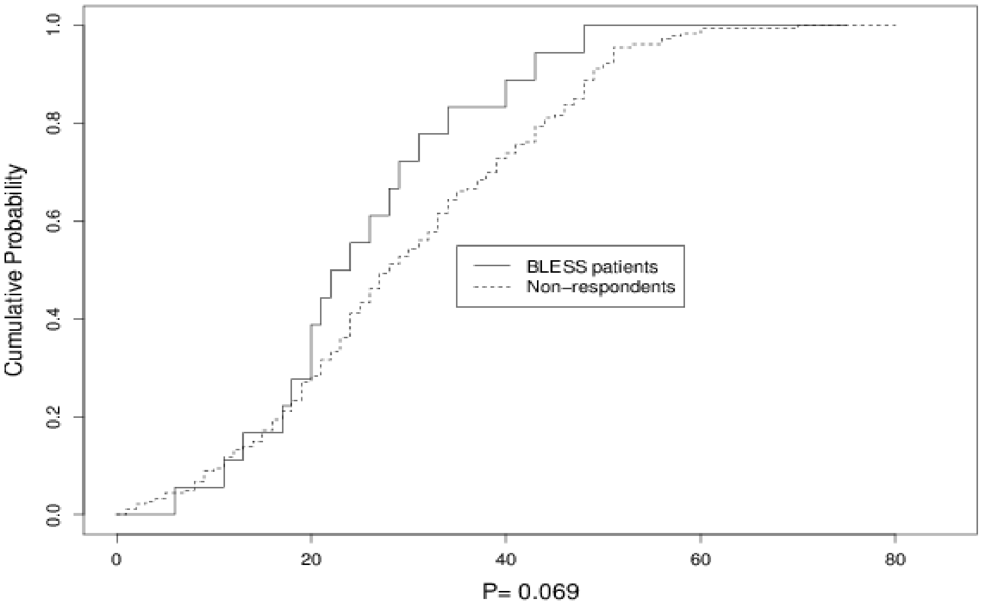


Figure 3: Time of onset of SLE manifestation from the date of SLE diagnosis (All)



young children or aging parents often don't take time for themselves(Woods-Giscombe CL 2010), but this trend is consistent with other studies. An investigation of the profile of medically non-adherent African-American patients with hypertension suggested that younger age, smoking, and female sex were associated with non-adherence, but marital status, education level, physician advisement, and household factors were not(Daniels et al. 1994). However, a study conducted by Uribe and colleagues (2004) to determine the baseline factors predictive of poor compliance with follow-up study visits in a longitudinal multiethnic lupus cohort study found that non-compliant patients were more likely to be young, unmarried, of African American ethnicity, live closer to the medical centers, and have longer disease duration and greater disease activity as assessed by the physician than the compliant patients.(Uribe et al. 2004)

All of these findings emphasize the importance of exploring the specific factors that limit and motivate the participation of African Americans in critical research activities. For example, during the course of the BLESS study, it became apparent that travel issues were preventing the full participation of the MUSC cohort. During follow-up phone calls for this project, many participants relayed that they could not participate in all aspects of the intervention because of complications related to travel. Some identified having to utilize Medicaid supported travel that required prior scheduling well in advance, but that even this type of transportation was not completely reliable. Others identified having to travel long distances, which required advance planning because of reliance on family members or friends to assist with transport. This information contributed to our knowledge concerning non-adherence and substantiated a need for further investigation of these issues. Specifically, this knowledge provided a foundation to investigate whether travel burden contributed to stress that may also impact the effectiveness of disease self-management programs.

CONCLUSION

There are multiple potential mechanisms by which every day and lifetime stress may adversely affect disease pathology in African-American lupus patients. While existing self-management programs have demonstrated improvements in biological markers of stress, psychological function, and physical function, interventions may not be reaching the largest portion of lupus cases due to differences in perceived benefits and barriers. In an effort to circumvent barriers to participation a priori, it is crucial to characterize patient-centric barriers to care in African-American lupus patients. Many Arthritis Foundation chapters have had difficulty disseminating arthritis self-management education programs. Additionally, many vulnerable populations have not been included in study samples (Hochberg, Altman et al. 1995; Austin, Maisiak et al. 1996; Edworthy et al. 2003; Haupt et al. 2005; Gaab et al. 2006; Goeppinger et al. 2007; De Abreu et al. 2009; Pena-Robichaux et al. 2010). Compliance is also a persistent problem in standardized programs. One study reported that less than 50% of a closed eligible population participated, even when Internet and small-group programs were offered repeatedly over many years(Bruce et al. 2007).

Such investigations have very high potential impact because of the likelihood that, if successful, information can be rapidly translated into improved research participation and delivery of health care with relevance to health disparities. Such findings could be used to develop and refine future lupus intervention activities, particularly in African Americans, who are at highest risk for the disease.

If widely implemented, morbidities and mortality related to lupus could be drastically reduced in African-Americans, and thus have a considerable impact on future research and policy decisions.

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