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### **The Challenges of Perceived Self-Management in Lupus.**

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## Abstract

**Objective:** Systemic lupus erythematosus is a chronic autoimmune disease with varied and unpredictable levels of disease activity. The ability to self-manage lupus is important in controlling disease activity. Our objective was to determine levels of patient activation toward self-management in lupus.

**Methods:** We used baseline results from the *MyLupusGuide*<sup>TM</sup> study that had recruited 541 lupus patients from ten centers. We used the Patient Activation Measure (PAM), a validated self-reported tool designed to measure activation towards self-management ability, as our primary variable and examined its association with demographic, disease-related, patient-provider communication and psychosocial variables captured in our study protocol. Univariable and multivariable linear regressions were performed using linear mixed models, with a random effect for centers.

**Results:** The average age was 50±14 years, 93% were female, 74% were Caucasian and the average disease duration was 17±12 years. The mean PAM score was 61.2±13.5 with 36% of participants scoring in the two lower levels, indicating low activation. Variables associated with low activation included being single, lower physical health status, lower self-reported disease activity, lower self-efficacy, use of more emotional coping and less distraction and instrumental coping strategies, and perceived lack of clarity in patient-doctor communication.

**Conclusion:** Low patient activation was observed in more than one third of lupus patients indicating a large proportion of patients perceived that they are lacking in lupus self-management skills. These results highlight a modifiable gap in perceived self-management ability among patients with lupus.

### Significance and Innovation:

- One third of persons with systemic lupus erythematosus report low activation and low confidence in self-managing their illness.
- Variables associated with low activation are: being single, lower physical health status, lower self-reported disease activity, lower self-efficacy, use of more emotional coping and less distraction and instrumental coping strategies, and perceived lack of clarity in patient-doctor communication.
- There is a need for an intervention to provide support and solutions that will help persons with SLE develop confidence in self-managing their illness.

## Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune, multi-organ inflammatory disease characterized by numerous clinical manifestations that affects preferentially young women. SLE is associated with a 15% increase in mortality, high morbidity and poor work outcomes. Despite an estimated prevalence of 1:1000 (1) SLE is mostly poorly understood from the general public and information about the disease and access to specialized care remains limited. The chronic nature of the illness, unpredictability of the disease course and complexity of treatment pose serious challenges to both patients and their treating physicians in disease management.

Activation refers to the ability and willingness to take on the role of managing one's own health and health care (2). This concept of activation may be used to evaluate preparedness and readiness to self-manage. Self-management is a crucial component of chronic disease management and is associated with positive health outcomes (3); however, in order to manage one's illness, one requires the knowledge and skills necessary to promote the confidence needed to actively participate in decision making about one's health care (4, 5). Activation in patients with chronic conditions has been shown to be independently associated with several useful skills such as: self-management behaviors (e.g. physical activity), use of self-management services, medication adherence, appropriate use of the health care system (e.g. having a regular source of care, not delaying care), consumeristic behaviors (e.g. preparing a list of questions for a doctor visit), improved chronic care self-management (e.g. keeping diary of blood pressure readings), control of chronic illness (e.g. better blood pressure reading, fewer hospitalizations) and health-related quality of life (6-9).

Previous studies examining factors associated with the degree to which patients with chronic conditions are activated for self-management have identified several associated factors under the following four categories: 1) Patient sociodemographics including age (10) (11), gender (12), marital status (13) and education (11); 2) disease related characteristics including disease duration, disease severity and health-related quality of life (HRQoL) (11) (14); 3) patient provider relational factors such as communication style (10); 4) and psychosocial factors including psychological distress (11), coping style (15), self-efficacy (16) and social support (11, 14). Most studies have focused on sociodemographic and disease related factors and few studies have simultaneously examined a

comprehensive set of factors, including modifiable psychosocial factors (17) (Supplementary Figure 1) that could be associated with level of patient activation for self-management.

We had the opportunity to study patient activation in SLE using the data from a study on "Measuring the Impact of *MyLupusGuide*<sup>TM</sup> (*MLG*<sup>TM</sup>) in Canada" (registered as NCT02950714 in ClinicalTrials.gov). *MLG*<sup>TM</sup> is a validated web-based program that was developed to facilitate engagement and self-management in patients with SLE (18). We report on the baseline findings of activation towards perceived health self-management in patients with SLE and the factors associated with lower activation.

### **Patients and Methods**

Patients for the *MLG*<sup>TM</sup> study were recruited from ten lupus clinics affiliated to the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS). CaNIOS centers follow a unified protocol that uses a clinical diagnosis of SLE (19) to classify study participants as having SLE. Each CaNIOS centre mailed invitations to all SLE patients who were at least 18 years of age and could read and write English or French. Patients who were willing to participate provided online consent and were asked to complete a series of online questionnaires after which they were given access to the *MLG*<sup>TM</sup> either immediately or three months later as part of a clinical trial. Analysis of PAM data was pre-planned as part of the *MLG*<sup>TM</sup> study (ClinicalTrials.gov #NCT02950714). We report here on the baseline data of the *MLG*<sup>TM</sup> study.

### **Assessments:**

**Patient Activation Measure (PAM):** The widely used 13-item PAM measures level of patient activation in their healthcare (20, 21). This measure is licensed and scored independently through Insignia Health® [<https://www.insigniahealth.com/products/pam-survey>]. This tool is designed to measure an individual's level of confidence, beliefs, knowledge, and skills about managing one's health. Respondents can answer with varying levels of agreement or disagreement (e.g., I know how to prevent problems with my health; I am confident that I can tell a doctor my concerns, even when he or she does not ask) on a 4-point Likert scale. This instrument has been shown to have strong psychometric properties. The PAM has been used in observational and interventional studies as a patient-centered measure to monitor changes in patient's experiences over time, with higher scores related to greater activation and associated with greater self-management, healthy behaviors,

medication adherence, better clinical outcomes and higher levels of satisfaction with services (22, 23). The PAM can be used as a continuous score from 0 to 100 or be divided into four levels. Level 1 (score  $\leq 47.0$ ) indicates the lowest level of activation (e.g., does not yet understand that an active role is important; Level 2 (score 47.1 to 55.1) (e.g., lacks knowledge and confidence to take action; Level 3 beginning to take action (score 55.2 to 67.0); and Level 4 (score  $\geq 67.1$ ) (e.g., maintaining behaviors over time) (24). Our primary outcome used the PAM score as a continuous variable. We classified Levels 1 and 2 as low activation.

**Socio-demographic questionnaires:** Baseline assessment of sociodemographic characteristics (age, sex, education, disease duration, Internet usage including access and time spent searching online for health information) were collected.

**Short Form 36 Version 1 (SF-36):** This generic measure of health status has been recommended for use in SLE, as it is both valid and reliable (25, 26) and it includes the important domain of vitality. In addition to scoring for each of the eight domains, an algorithm also allows calculation of normalized scores for physical and mental function, the physical component summary (PCS) and the mental component summary (MCS) scores (27). Individual domain scores range 0-100 with higher scores indicating better function. Additional computations are required to transform the raw data into physical (PCS) and mental (MCS) components summary scores normalized for a reference population at 50. Any scores below 48 on the PCS or MCS reflect a clinically relevant impairment in health status.

**Systemic Lupus Activity Questionnaire (SLAQ):** This 25-item self-reported questionnaire assesses disease activity in nine organ systems and has demonstrated positive predictive values ranging from 56 to 89% for detecting clinically significant disease activity (28). It has been found to have adequate reliability and construct validity (29). Scores can range from 0–44 with higher scores indicating higher disease activity that correlate with the physician-completed Systemic Lupus Activity Measure (SLAM) (30).

**Lupus Damage Questionnaire Index (LDQI):** This 56-item self-reported questionnaire assesses disease damage across 12 organ systems. It has been found to have construct validity with good correlations with the Systemic Lupus International Collaborating Clinics/ American College of Rheumatology Damage Index (SDI) for most organ systems. It may serve as a useful and reliable

alternative to the SDI in assessing SLE-related damage in population studies (31). LDIQ scores range from 0 to 43 with higher scores indicating greater damage.

**Lupus Self-Efficacy Scale (LSES):** The LSES adapted for lupus from the Arthritis Self-efficacy Scales (32) was used to measure patients' confidence related to lupus-specific domains. This 11-items version assesses level of confidence in managing or decreasing lupus-related symptoms (i.e. fatigue, mood). The construct and concurrent validity of this scale has been demonstrated (33). Self-efficacy has been found to be an important determinant in the adoption of self-management approaches among patients with arthritis (34). LSES scores range 0-110 with higher scores indicating greater self-efficacy.

**Center for Epidemiological Studies-Depression (CES-D):** The CES-D is a 20-item scale designed to measure symptoms of depression in the general population. The CES-D has been widely used in patients with chronic medical diseases and has been found to be more appropriate than other depression indices for patients with rheumatic disorders (35). CES-D scores range 0-60 with higher scores indicating greater depression. A score of 16 or greater has been used to identify individuals at risk for clinical depression, with good sensitivity and specificity and high internal consistency (36).

**Morisky Levine scale (MLS-4):** The MLS-4 is a valid and simple self-report 4-item scale that measures adherence to medication (37). It applies to all medications and diseases and does not measure any particular period. Scores range from 0-4 with low scores indicating better adherence.

**Coping with Health Injuries and Problems (CHIP):** This 32-item questionnaire assesses coping strategies typically used when dealing with health problems (38). Its four subscales include distraction (e.g. to dream of agreeable things rather than disease), palliative (e.g. to save his/her energy), instrumental (e.g. to look for efficient treatments) and emotional coping (e.g. to feel angry because of the disease). This instrument has been shown to have good psychometric properties and has been recommended for use with different medical populations (39). Each of the four subscales range 1-40. Higher values in each subscale are associated with greater use of the coping related strategy.

**Modified Medical Outcomes Study Social Support Survey (MMOS SSS):** The MMOS SSS is a seven item shortened version (40) of the original scale (41) that measures perceived support from one's social network related to emotional, tangible and affectionate domains. Higher scores indicate



higher perceived social support. Good internal consistency has been reported for the original version (41).

**Interpersonal Processes of Care Survey - Short Form (IPC-SF):** The IPC-SF (42) assess three domains of patients' experiences with patient-doctor communication including, communication (lack of clarity, elicited concerns, explained results), patient-centered (decision making), and interpersonal style (compassionate/respectful encounters with health care providers). For this study we used the following five subscales: lack of clarity, elicited concerns, explained results, patient-centered decision-making, and compassionate interpersonal style. Scores for each scale range from 0 to 4. With the exception of the communication subscale "lack of clarity", higher scores indicate better experiences of the specific dimension, such as being provided with more explanations or more instances of being involved in treatment decisions. High scores in the communication subscale "lack of clarity" indicates worse experiences of receiving and interpreting disease related information.

**Analysis.** Descriptive statistics are presented as mean with standard deviation, or frequency with percentage. Univariable linear regressions were done using linear mixed models, with a random effect for centers. Results are presented as regression coefficient ( $\beta$ ) for continuous variables, where the regression coefficient ( $\beta$ ) represents a change in PAM score by a beta amount for a one unit increase in the variable, or as a mean PAM for categorical variables, with their standard error and p-value. Variables with a p-value below 20% in the univariable models, that were not collinear, and with a clinical relevance, were included into a mixed effect multivariable model with random center effect like above. In order to understand counterintuitive results, where a coefficient sign was different between univariable and multivariable models, several bivariable models were tested. In these, the association of interest was adjusted for each of the other covariables separately.

## **Results**

**Patients' characteristics:** Of 1916 patients who were mailed invitation letters, 541 (28%) provided consent and completed the first series of questionnaires. One patient was removed from the analyses due to unreliable response data resulting in a total of 540 patients with complete data. Tables 1, 2 and 3 show the baseline demographic, disease and psychosocial characteristics of 540 patients with SLE and their association with activation towards health self-management in univariable models.

**Patient activation:** The average PAM score was  $61.1 \pm 13.5$  with 16%, 20%, 42% and 22% respectively in levels one, two, three and four. Thirty-six percent of patients scored in levels one or two, indicating low activation towards perceived health self-management.

**Demographic characteristics:** The mean age was  $50 \pm 14$  years, 93% were female, 39% had completed university and 16% had done post-graduate studies, 65% were married, 54% were employed and 20% were work disabled. Seventy-four percent of participants were Caucasian, 11% were Asian, 5% were Black and 10% reported being of other ethnicity. Participants reported using computers an average of  $14.5 \pm 13.7$  hours per week and 216 (41%) participants reported using the computer to search for health information frequently to very frequently.

**Disease characteristics:** The average disease duration was  $17 \pm 12$  years and ranged between 0-63 years. The average SF-36 PCS and MCS scores were  $39 \pm 12$  and  $45 \pm 12$  indicating poor physical and mental function. The self-reported lupus disease activity average was  $14.0 \pm 8.0$  (range 0-41) indicating low disease activity and lupus damage was moderate with an average of  $3.5 \pm 3.1$ .

**Psychosocial characteristics:** The mean CES-D score was  $15.6 \pm 10.7$ , with 232 (43.1%) of the sample scoring above the depressed mood cut-off score ( $\geq 16$ ) indicating suspected depression. For CHIP, the use of instrumental coping was most frequent and emotional preoccupation was the least frequently used coping mechanism.

#### **Associations with lower PAM in patients with SLE:**

Results of univariable analyses are reported in Tables 1, 2 and 3. The univariable results demonstrate that lower PAM scores were associated with level of education, more disability, shorter disease duration, higher self-reported disease activity, lower physical and mental function (SF-36 PCS and MCS scores), and lower adherence to medication, reflected by a higher MLS-4 score (Tables 1 and 2). Among the psychosocial characteristics (Table 3), lower PAM scores were associated with more depression, more use of emotional coping (CHIP), lower self-efficacy, and more perceived "lack of clarity" in patient-doctor communication IPC subscale (Table 3). Higher PAM scores were associated with use of better coping strategies (distractive and instrumental) and better experiences with patient-physician communication (subscales "elicited concerns", "explained results", "decision making", "compassionate style") (Table 3).

Results of the overall multivariable model that included combined demographic, disease and psychosocial characteristics in the same analytical model are presented in Tables 4, 5 and 6, respectively. Lower PAM scores were associated with being single, lower physical health, and lower self-efficacy. Of note, contrary to the result found in the univariable analysis, the multivariable model showed that lower PAM scores were associated with lower disease activity.

Among the CHIP coping strategies assessed, lower PAM scores were associated with higher use of emotional coping and less use of distractive and instrumental coping strategies. Among the interpersonal processes of care subscales, lower PAM scores were associated with more perceived "lack of clarity" on this IPC subscale.

### **Discussion**

Our primary outcome was to assess the perceived self-management ability in patients with SLE. The PAM is a valid and reliable tool to measure knowledge, skills and confidence needed for self-management. Our findings showed that more than one third of the lupus patients who participated in this study scored low for activation as measured by the PAM. Although a limitation of our study is that we did not measure self-management directly, these PAM scores suggest that a significant proportion of our participants reported a lack in knowledge, skills or confidence in self-managing their disease. Interestingly, these results reflect what has been described in the general population of Northern Europe with proportions of low activation ranging from 18% to 37% (43) suggesting that the level of activation in a population may not be related to being sick.

We were also interested in determining which factors were associated with lower activation in SLE. Lower self-assessed physical health, measured by the physical health component of the SF36, was associated with a lower PAM score. This finding has been previously reported in other chronic disease populations (11, 14) and may suggest that persons with poor physical health may have limited energy and may benefit from more tailored interventions with clear and specific instructions to take small steps to improve their engagement in self-care (44).

We found a positive association between self-reported lupus disease activity and the PAM scores in the multivariable model, while the association was negative in the univariable model. The result from the univariable model is in accordance with the notion that more patient activation is associated with better health outcomes (3). The reverse association in the multivariable model might be explained by

the covariates we used in the model. For example, higher self-efficacy or physical and mental health status may give patients with more self-reported lupus activity an incentive to be more engaged in their disease management, resulting in a positive association with PAM.

Our results may suggest that when disease activity is low, persons with SLE may be less motivated to continue to follow self-care strategies and increase their use when the disease is more active. However, the importance of maintaining self-care long-term to prevent future complications is essential. Providers caring for patients with lupus need to emphasize the importance of self-care as a long-term self-management strategy.

When viewed descriptively the means on the CHIP subscales were similar to those previously reported by women in other medical populations (38). Among the health-related coping strategies, the use of more emotional oriented coping strategies was associated with lower patient activation towards health self-management in this cross-sectional study. Focusing on the emotional aspects of the illness process has been associated with deficits in quality of life and increased psychological distress in chronic disease populations, including SLE (45, 46). We extend these findings to SLE by demonstrating an association between higher levels of emotional preoccupation and less patient activation.

Distraction coping pertains to the attempts made to cope by focusing on more pleasant experiences or seek the company of others. Participants who relied less on these strategies reported less activation towards self-management of their health. The use of distraction coping has been associated with avoidance and poorer health outcomes in the long-term, particularly when problems are manageable (47, 48). Yet, items in this coping subscale include the use of social diversion to cope with health such as inviting others to visit and enjoying the attention of friends and family and more positive forms of distraction such as thinking about the good times I have had.

Consistent with prior studies examining more adaptive coping strategies used by persons with SLE (49, 50), instrumental coping which involves seeking knowledge about the illness and/or medical advice, and use methods to problem solve and set goals were associated with higher patient activation. Our findings suggest that interventions designed to increase patient activation should include these types of active coping strategies to empower patients with the skills needed to better self-manage their condition.

Patients who reported a lack of clarity in trying to understand their doctor due to the use of technical terms and to the speed with which the information was transmitted reported lower activation. In other chronic illness populations, poorer patient provider communication has been associated with worse patient self-care behaviors and adherence to treatment regimens (51-53). Few studies have examined the relationship between patient-physician communications and activation for health self-management in SLE. Our findings suggest the importance of using non-technical terms when conveying medical information to patients, as well as efforts to ensure that patients have understood information. Digital technology platforms such as the web-based interactive navigator *MyLupusGuide*<sup>TM</sup> that can be accessed 24/7 by the patient may be an effective adjunctive modality to ensure that important information is conveyed and understood by the patient.

We acknowledge some limitations to our study. We used the baseline data from a clinical trial that will be published separately to describe patient activation in a sample of patients with lupus. As such, this is a cross-sectional study and our analyses do not allow inferring cause to effect relationships on the associations that we are reporting. For example, although we observe an association between poor physical health, lack of clarity in physician-patient communication, or instrumental coping and low patient activation, we cannot conclude that low activation is a result of these other factors. Our study sample was recruited from the Canadian Network for SLE (CaNIOS) longitudinal observational study. We recruited in total a quarter (28%) of the CaNIOS cohort. Sociodemographic and disease characteristics of our study sample such as sex, race, marital status, education, work disability, and self-reported disease activity, damage and health status reflected those of the CaNIOS cohort (Supplementary Tables 1 and 2). We observed however that our sample was slightly older (age  $50.07 \pm 14.15$  for MLG vs  $47.97 \pm 15.18$  for CaNIOS) and with longer disease duration (average disease duration  $16.91 \pm 11.93$  for MLG vs  $12.25 \pm 12.18$  for CaNIOS) than that of the general CaNIOS cohort which may have affected the attitude of our participants regarding self-management. In addition, unmeasured differences may have been present and undetected. A selection bias of our participants is possible and we must be cautious when generalizing our findings to that of all lupus patients. Our participants were recruited from lupus tertiary care centers and may not be entirely representative of the full spectrum of persons with SLE as they may reflect a population that is more Caucasian, better educated than the average with access to more comprehensive specialized care and

more information about lupus. Furthermore, our study was conducted online requiring patients to have access to the Internet via computer, tablet or Smartphone. Since we could not measure the ability to master the info-route, we could only assume that they mastered the ability to use these devices and skills to complete the online tasks required for the study. Characteristics may differ between those who have computer devices and Internet availability from those without; however, we were unable to collect that information because our study was conducted solely online and unable to survey patients without internet access.

Strengths of our study include a robust online methodology, a large sample, and a comprehensive survey that captured several psychosocial characteristics that influence health care behaviors and patient activation.

Interventions to improve activation are becoming increasingly important as research shows that highly activated individuals tend to have a wide range of improved health related outcomes (6) . We observed low patient activation in more than one third of a large sample of lupus patients participating in a study of *MyLupusGuide*<sup>TM</sup>. These findings suggest that this vulnerable population needs additional support resources to improve their ability in the self-management of SLE. We identified modifiable factors associated with low activation and recommend interventions that focus on strategies to improve more adaptive coping and patient-doctor communication to help patients better self-manage their disease.

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**Table 1: Descriptive and univariable analysis of demographic characteristics using PAM as principal variable.**

Variable (n)	Levels	Mean $\pm$ SD or N (%)	$\beta$ or Mean PAM	Standard error	Pvalue
Age (534)		50.07 $\pm$ 14.15	0.02	0.04	0.66
Gender (528)	Male	38 (7)	59.02	2.36	0.31
	Female	490 (93)	61.32	1.11	
Marital (537)	Single	106 (20)	59.04	1.54	<b>0.07</b>
	Married	351 (65)	61.76	1.09	
	Widowed	19 (4)	67.97	3.18	
	Separated	22 (4)	62.30	2.97	
	Divorced	39 (7)	59.73	2.29	
Education (538)	High school	79 (15)	60.27	1.71	<b>0.03</b>
	Some post-secondary	74 (14)	63.80	1.78	
	Some university	89 (17)	58.50	1.63	
	University-complete	211 (39)	60.89	1.22	
	Post-graduate studies	85 (16)	64.12	1.66	
Work disability (535)	Yes	109 (20)	57.29	1.54	<b>&lt; 0.01</b>
	No	426 (80)	62.32	1.07	

PAM= Patient Activation Measure;  $\beta$  is the regression coefficient of the model and it represents a change in PAM score by a beta amount for a one unit increase in the variable studied.

**Table 2: Descriptive and univariable analysis of disease characteristics using PAM as principal variable.**

Variable	N	Mean ± SD or N (%)	β or Mean PAM	Standard error	Pvalue	PA M= Pati ent Acti vati on Mea sure; SLA Q = Syst emic Lup
Disease duration (years)	533	16.91 ± 11.93	0.12	0.05	<b>0.01</b>	
SLAQ	540	14.01 ± 8.00	-0.31	0.07	<b>&lt; 0.01</b>	
LDIQ	540	3.53± 3.06	-0.04	0.19	0.83	
SF36-PCS	535	39.05 ± 11.98	0.30	0.05	<b>&lt; 0.01</b>	
SF36-MCS	535	44.76 ± 11.65	0.23	0.05	<b>&lt; 0.01</b>	
MLS-4 scores N (%)	540				<b>&lt; 0.01</b>	
0		210 (39)	63.13	1.19		
1		202 (37)	61.50	1.22		
2		77 (14)	58.85	1.70		
3		30 (6)	59.93	2.54		
4		21(4)	52.02	3.01		

us Activity Questionnaire; LDIQ = Lupus Damage Index Questionnaire; SF36-PCS = Short Form 36 Version 1 physical component scale; SF36-MCS = Short Form 36 Version 1 mental component scale; MLS-4=Morisky Levine Scale-4;β = the regression coefficient of the model and represents a change in PAM score by a beta amount for a one unit increase in the variable studied.

**Table 3: Descriptive and univariable analysis of patient-provider communication factors and psychosocial characteristics using PAM as principal variable (N=540).**

Variable	N	Mean±SD or N(%)	β or Mean PAM	Standard error	Pvalue
CESD - Depression	538	15.61 ± 10.68	-0.32	0.05	< <b>0.01</b>
CHIP - Distraction	539	24.70 ± 6.16	0.56	0.09	< <b>0.01</b>
CHIP - Palliative	539	24.06 ± 4.85	0.15	0.12	0.21
CHIP - Instrumental	539	29.27 ± 5.26	0.78	0.11	< <b>0.01</b>
CHIP - Emotional	539	19.84 ± 7.60	-0.45	0.07	< <b>0.01</b>
LSES - Self-efficacy	539	69.04 ± 23.60	0.26	0.02	< <b>0.01</b>
MOS SSS - Social support	539	20.16 ± 6.68	0.46	0.08	< <b>0.01</b>
IPC - Lack of Clarity	535	0.75 ± 0.77	-5.06	0.73	< <b>0.01</b>
IPC - Elicited Concerns	535	3.24 ± 0.74	4.10	0.77	< <b>0.01</b>
IPC - Explained Results	535	2.96 ± 0.99	3.19	0.58	< <b>0.01</b>
IPC - Decision Making	531	2.58 ± 1.17	2.37	0.50	< <b>0.01</b>
IPC - Compassionate	535	3.20 ± 0.84	3.13	0.68	< <b>0.01</b>

PAM = Patient Activation Measurement. CESD = Center for Epidemiological Studies-Depression; CHIP = Coping with Health Injuries and Problems; LSES = Lupus Self-Efficacy Scale; MOS SSS = Medical Outcomes Study Social Support Survey; IPC-SF Interpersonal Processes of Care Survey - Short Form; β = the regression coefficient of the model and represents a change in PAM score by a beta amount for a one unit increase in the variable studied.

**Table 4: Multivariable model using PAM as principal variable: Demographics section.**

Variable	Levels	$\beta$ or Mean PAM	Standard error	Pvalue
Group*	Now	62.62	1.82	0.93
	Later	62.42	1.82	
Marital	Single	59.40	1.60	<b>0.04</b>
	Married	60.52	1.37	
	Widowed	68.39	2.96	
	Separated	62.56	2.79	
	Divorced	61.73	2.21	
Education	High school	62.13	1.88	0.10
	Some post-secondary	63.50	1.93	
	University (incomplete)	60.70	1.83	
	University (complete)	61.50	1.59	
Work disabled	Yes	61.46	1.84	0.13
	No	63.58	1.42	

Tables 4, 5 and 6 report on the results of the same overall multivariable model but divided into three sections. Table 4 reports on the demographic variables for the overall model. PAM= Patient Activation Measure;  $\beta$  is the regression coefficient of the model and it represents a change in PAM score by a beta amount for a one unit increase in the variable studied. \* The variable «Group» is included in the multivariable model as the study consists of a randomized controlled trial (results of the intervention will be presented separately) and randomization was done by centers, one group of centers being invited to receive the intervention NOW and the other 3 months LATER. Although unlikely with randomization, belonging to one group or the other could have affected baseline characteristics and we included the variable «Group» in our multivariable analysis to adjust for this.

**Table 5: Multivariable model using PAM as principal variable: Disease characteristics section.**

Variable	Levels	$\beta$ or Mean	Standard	Pvalue
		PAM	error	
Disease duration (years)		0.06	0.05	0.21
SLAQ - disease activity		0.28	0.10	< <b>0.01</b>
SF36-PCS – physical health status		0.16	0.07	<b>0.02</b>
SF36-MCS –mental health status		-0.03	0.06	0.68
MLS-4	0	62.50	1.48	0.90
	1	63.02	1.48	
	2	62.38	1.80	
	3	63.81	2.46	
	4	60.88	2.97	

Tables 4, 5 and 6 report on the results of the same overall multivariable model but divided into three sections. Table 5 reports on the disease characteristics variables for the overall model. PAM= Patient Activation Measure; SLAQ = Systemic Lupus Activity Questionnaire; SF36-PCS = Short Form 36 Version 1 physical component scale; SF36-MCS = Short Form 36 Version 1 mental component scale; MLS-4=Morisky Levine Scale-4;  $\beta$  is the regression coefficient of the model and it represents a change in PAM score by a beta amount for a one unit increase in the variable studied.



**Table 6: Multivariable model using PAM as principal variable: Patient-provider communication factors and psychosocial characteristics sections.**

Variable	$\beta$ or Mean	Standard	Pvalue
	PAM	error	
CHIP - Distraction	0.20	0.09	<b>0.03</b>
CHIP - Palliative*	-0.04	0.11	0.74
CHIP - Instrumental*	0.53	0.11	<b>&lt; 0.01</b>
CHIP - Emotional*	-0.17	0.08	<b>0.04</b>
LSES - Self-efficacy	0.15	0.03	<b>&lt; 0.01</b>
MOS SSS - social support	0.11	0.09	0.24
IPC - Lack of Clarity	-3.38	0.71	<b>&lt; 0.01</b>
IPC - Elicited Concerns	0.30	1.01	0.77
IPC - Explained Results	1.08	0.65	0.10
IPC - Decision Making	0.70	0.54	0.20
IPC - Compassionate	-0.86	0.91	0.35

Tables 4, 5 and 6 report on the results of the same overall multivariable model but divided into three sections. Table 6 reports on the patient-provider communication factors and psychosocial characteristics variables for the overall model. PAM = Patient Activation Measurement. CHIP = Coping with Health Injuries and Problems; LSES = Lupus Self-Efficacy Scale; MOS SSS = Medical Outcomes Study Social Support Survey; IPC-SF Interpersonal Processes of Care Survey - Short Form;  $\beta$  = the regression coefficient of the model and it represents a change in PAM score by a beta amount for a one unit increase in the variable studied.