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Rehabilitation Research and Training Center (RRTC) on Research and Capacity Building for Minority Entities

Disease Impact of Lupus on Functioning & the Need for Vocational Rehabilitation Counseling Services: Implications for Diverse Racial/ Ethnic Populations

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LU-RRTC State-of-the-Science Conference

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Presentation Objectives

- + Discuss the impact of race/ethnicity on patients with Lupus
- + Define Lupus and the potential impact on health and well being
- + Discuss the impact of Lupus on patient's functional status
- + Assess the levels of disability in patients with Lupus
- + Assess the vocational and educational support needs of patients with Lupus



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BACKGROUND

- + SLE- Autoimmune disease in which the body's immune system attacks its own organs resulting in significant morbidity and mortality.
- + This chronic disease impacts all areas of patients' lives including physical, social, mental, and emotional functioning, often resulting in significant disabilities and poor quality of life (Ekblom-Kullberg, Kautiainen, Alha, Leirisalo-Rep & Julkunen, 2015; Robinson et al., 2010)
- + Incidence of SLE has tripled over the past 4 decades (Macejova, Zarikova, & Oetterova, 2013).
 - + There are 1.5 million people with Lupus in the United States, with approximately 160,000 new cases diagnosed annually (LFA, 2016).

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BACKGROUND

- + Lupus is like a fingerprint- no Lupus is exactly the same
- + There is no way to predict which or how many organ systems Lupus will affect in each individual patient.
- + No cure for Lupus, it has a relapsing and remitting course.
- + Among the most common organ systems involved include:
 - + CNS/Brain
 - + Kidneys
 - + Lungs
 - + Blood
 - + Skin
 - + Joints



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BACKGROUND

- + 2 to 4 times more common in non-white racial/ethnic groups, particularly in African Americans, Asians, Hispanic & First Nation/Native Americans.
- + Studies suggest Lupus occurs earlier in life for Hispanic and African-American individuals.
- + Higher rates of morbidity, mortality and disability among Hispanic & African Americans.
- + More commonly seen in women, with 90% of patients being women between the ages of 15 and 44.
- + (CDC, 2015; Pons-Estel, Alarcon, Scofield, Reinlib & Cooper, 2008).

Background

Individuals being diagnosed at a younger age, African Americans and persons from lower socioeconomic backgrounds have been found to have:

- more severe disease,
 - poorer physical, psychological & social functioning
 - higher mortality rates
- (Danoff-Burg & Friedberg, 2009; Macejova et al., 2013; Mina & Brunner, 2010; Pons-Estel et al., 2008).

BACKGROUND

- + Children's Hospital at Montefiore: Pediatric Rheumatology Division
- + Disagreement between provider & patients' assessment level of disease activity
- + Disability and impaired functionality in individuals with Lupus are often underdiagnosed- due to the complicated relapsing and remitting nature of the disease
- + This resulted in non-compliance, lack of follow up, poorer outcomes for patients

Discordance

- + Discordance is defined as the difference between the physician and patient evaluation of their disease status and well-being.
- + Patients were complaining of difficulty
 - + Going to school
 - + Working
 - + Complete activities of daily living
- + Providers were focusing on lab values and their own perceptions of how patient was doing

BACKGROUND

- + Research - 98% of Lupus patients state they have unmet needs related to their ability to function in the following areas:
 - physical,
 - psychosocial,
 - psychological functioning

(Macejova et al., 2013; Schmeding & Schneider, 2013; Danoff-Burg & Friedberg, 2009).

BACKGROUND

- Disability and impaired functionality in individuals with Lupus are often underdiagnosed, due to:
 - the complicated relapsing and remitting nature of the disease (i.e., functioning alternating with a period of loss of functionality)
 - poor communication & inclusion of functional status as a measure of well being and disease status

BACKGROUND

- + Studies have found level of work disability among individuals with Lupus -ranges from 32 % to as high as 63%.
(Macejova et al., 2015; Lawson et al., 2014; Schmeding & Schneider, 2013; Almehed, Carlsten & Forsblad-d'Elia, 2010; Baker & Pope, 2009).
- + Research has also found that impairments accumulate as the disease processes of Lupus progress. (Schmeding & Schneider, 2013).
- + As many as 40% of individuals have been found to no longer be employed within 3.4 years of being diagnosed with Lupus (LFA, 2016).

BACKGROUND

- + Lupus Alliance (2015) highlights that accommodations such as 504 IPE plans should be provided for children/adolescents with Lupus.
- + The organization suggests considerations should also be provided for persons with Lupus in higher education settings.

First Study: Manuscript Under Review

- Childhood Arthritis and Rheumatology Research Alliance (CARRA) retains a national database collected from pediatric rheumatology centers and researchers across North America.
- We evaluated a data set from CARRA performing a secondary data analysis for a subset of 861 Lupus patients between the ages of 12 and 21.

First Study

- Secondary analysis of data from CARRA pediatric rheumatology centers in the US and Canada, from 2010-2015.
- The level of discordance between patient and provider's assessment of disease status was analyzed,
- We also assessed the relationship between levels of discordance and gender, ethnicity/race, pain, functional assessment, and use of antidepressants.

Variables

●Patient

- Perception of level of disease activity
- Level of functional status
- Pain level
- Psych medications

●Provider

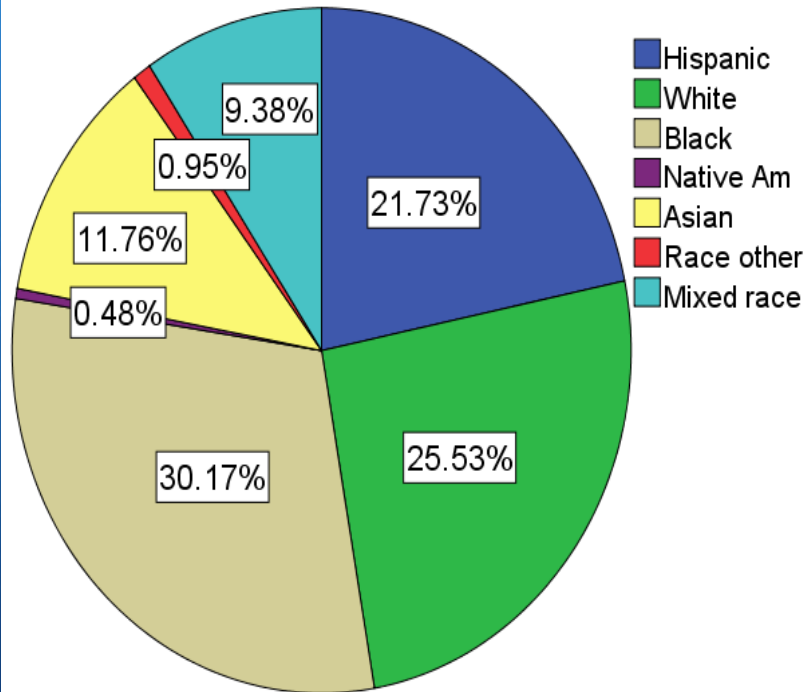
- Perception of level disease activity
- Level of functional status
- Lab values for Lupus disease activity monitoring

DEMOGRAPHICS

Variable	Percentage/Frequency/Mean
GENDER	Female=82.9% (N=712) Male=17.1%(N=147)
INCOME	17.7% (N=152) <25,000 15.1% (N=130) 25-49,999 8.7% (N=75) 50-74,999 7.0% (N=60) 75-99,9999 7.8% (N=67) 100,000-150,000 5.8% (N=50) 150,000+ 37.3% (N=320) Not reported
INSURANCE STATUS	4.1% (N=35) No insurance 92.2% (N=792) Insured
AGE	M=16.57 (SD=2.26)

Sample Demographics Cont.

Figure 1. Breakdown of Race/Ethnicity for Sample



Race/Ethnicity	US Census Data 2015
White	61.6%
Black	13.3%
Hispanic	17.6%
Asian	5.6%
Native American	1.2%
Multi-Racial	2.6%
Native Hawaiian/Pacific Islander	.2%

Data Analyses

Discordance

Calculated by subtracting the physician's rating of disease activity *from* the patient's rating of disease activity level to arrive at a discrepancy level.

Positive score-

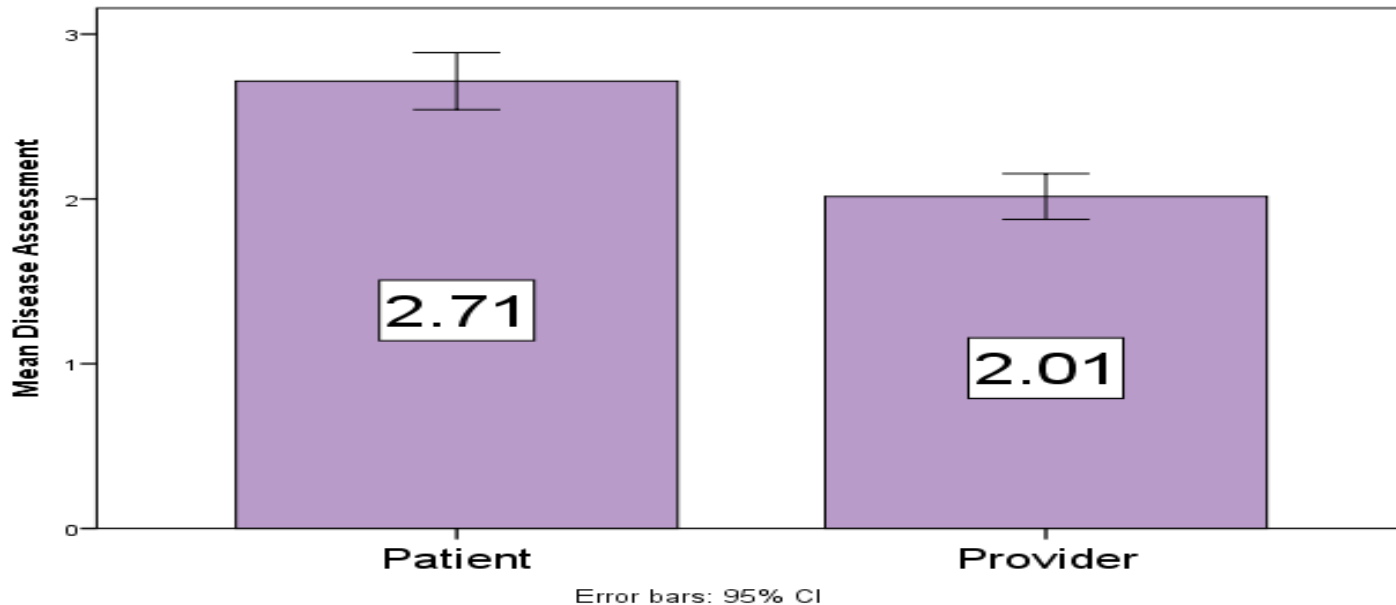
reflected a patient indicating greater illness than the provider.

Negative scores-

reflected situations where the provider indicated greater illness than the patient.

Patient/Provider Global Assessment of Illness

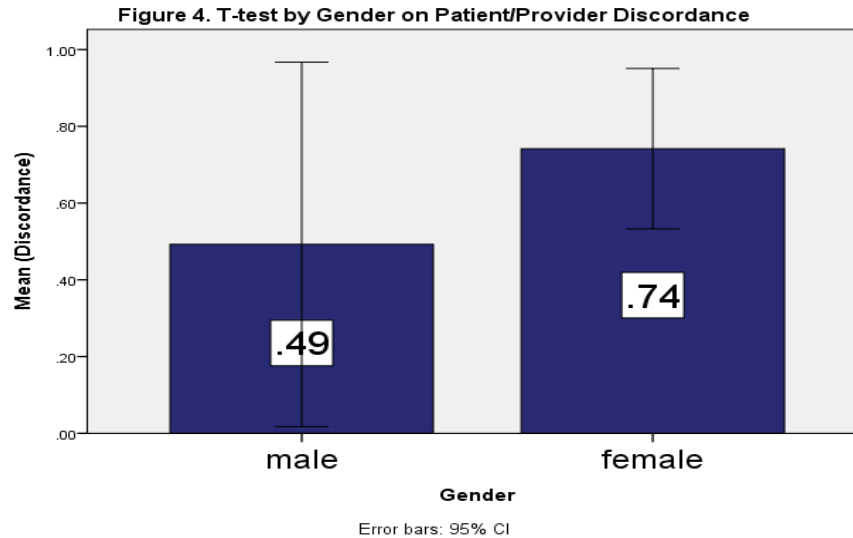
Figure 3. Paired T-test between Physician and Patient Global Assessment of Disease Status



Paired samples t- test ($t(793)=7.28$,
 $p<.001$)

Patients rated themselves as sicker than their
provider did.

Gender and Discordance

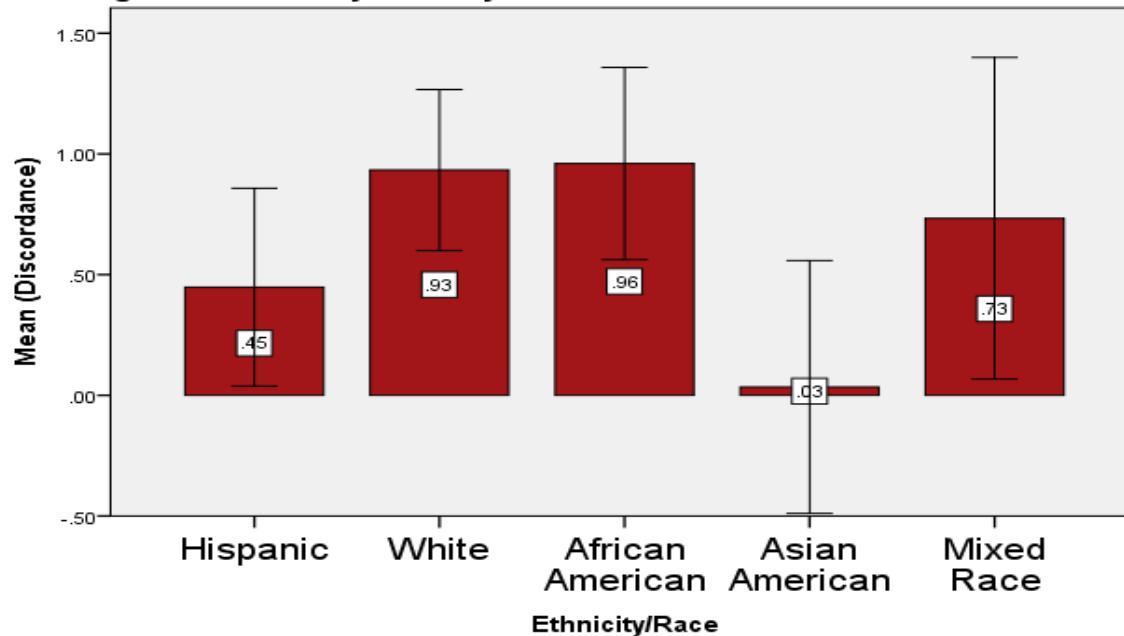


Independent samples t test ($t(790) = -.96$, *ns*)

No gender differences on patient/provider discordance

Analysis of Patient/Provider Discordance by Ethnicity/ Race

Figure 7. ANOVA by Ethnicity/Race on Patient/Provider Discordance



Error bars: 95% CI

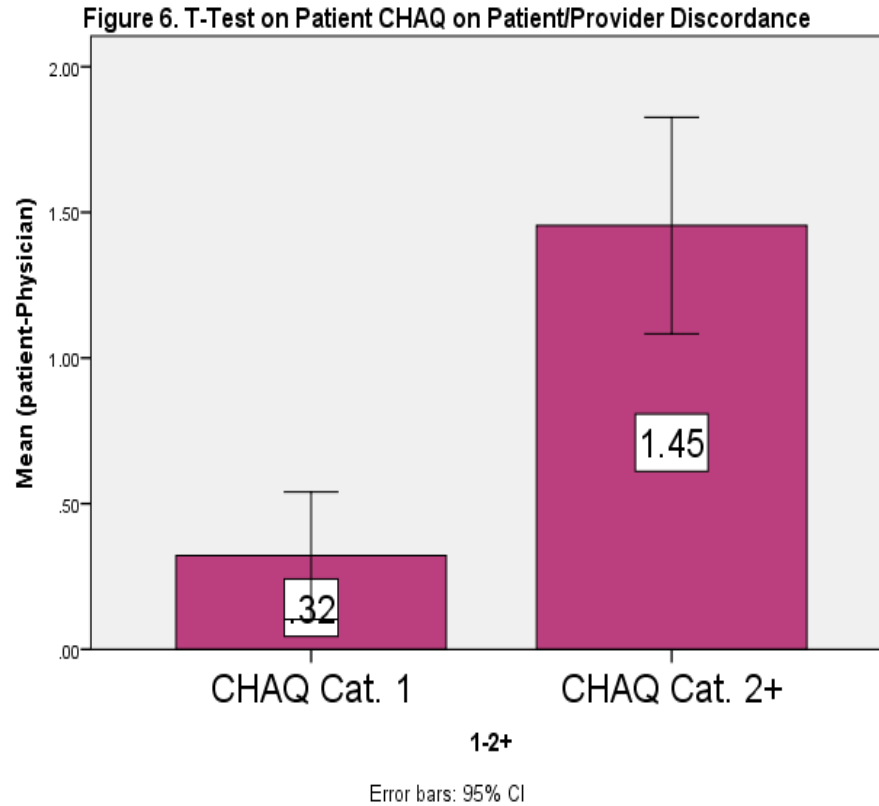
The One-way ANOVA was significant ($F(4,765)=2.58, p<.05$).

African American individuals had the highest discordance and Asian individuals the lowest.

Functional Status

Functional Status/disability	Patient	Provider
Full functioning	65.5%	79.4%
Mild disability	17.1%	12.0%
Moderate	11.5%	4.3%
Severe	1.6%	0.8%

Discordance & Functional Status



$t(774) = -5.43, p < .001$

Major findings

- Patients rated themselves as sicker than their provider did.
- The more pain the patient reported the greater the discordance between patient and provider.
- Greater discordance for those taking psych medications.
- Patient's rated their functional status as significantly worse than the providers did.

Functioning & Lupus

- Our findings highlighted - potential lack of provider's recognition of client's functioning.
- Participants stated they are having difficulties in performing simple daily activities.
- We wanted to know if these clients are being referred for vocational rehabilitation services and if they are receiving them.
- Maybe lost opportunities for providing support services to reduce disability levels and optimize functioning.

2nd Study: Research Rationale

No data have been published on how providers and individuals with Lupus work together to determine their disabilities and which accommodations, if any, should be in place.

Further, it is not understood what variables providers consider regarding the impact Lupus is having on individual's educational, physical and psychosocial functioning or whether providers know what services they can or should refer these individuals for.

CURRENT STUDY OBJECTIVES

+ Research Foci

- + The purpose of this study was to survey individuals with Lupus about whether:
 - their disease impacted their education, work and social functioning,
 - they were ever referred for vocational rehabilitation services,
 - if they received educational support services or vocational rehab services.
- + The relationship between receiving vocational/educational counseling services and educational and employment.



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METHOD: Sampling

- + We accessed 2 organizations that have online discussion/support sites for persons with Lupus to learn and communicate about their disease.
 - The Lupus Foundation of America
 - Lupuschick.com
- Study participants provided informed consent on-line, before administration of the survey with Google forms.
- IRB approval was obtained and ethical standards were followed throughout the study.



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METHOD (continued)

- + N=178 participants that completed the survey
- + 174 females and 2 males (n=2 missing)
- + Average age of the participants was $M=38.48$ (SD=11.11)
- + Average time since diagnosis $M=7.11$ (SD=7.69) years ago



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KEY INFORMANT CHARACTERISTICS

Profile of Participants

Highest Education Level	%
Some college	40%
Finished college	26%
Completed HS	15%
Masters/Professional Degree	13%%
Some HS	4%
PhD/Terminal degree	1%
Other	1%



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KEY INFORMANT CHARACTERISTICS

(continued)

Profile of Participants

Occupational Status		%
Employed Full time		38%
Unable to work due to illness/disability		38%
Employed part time		13%
Full time school		5%
Not going to school due to disability/illness		2%
Going to school part time		1%
Other		4%



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METHOD SURVEY

- Our survey



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IMPACT ON SCHOOL

Has your Lupus affected your ability to get an education?	%
Leave school because I could not concentrate	10.7 %
Absent because of my Lupus too often to keep up with school	10.2%
Leave school because I was too tired	8.5 %
Go to school part time instead of full time	8.5%
Leave school because of the traveling to school/home and moving around the buildings/campus	5.1%

IMPACT ON WORK

Has your Lupus affected your ability to work?	%
Lupus impacted the number of sick days I take	41.2
Lupus impacted the number of hours I can work	35.6
I quit a job because of my Lupus	28.2
Adjusted my career choice	21.3
Wanted to work full time but had to change to part time	12.9
I was fired because of my Lupus	11.3

IMPACT ON HOME LIFE

Has your Lupus affected your ability to live your life?	%
Ability to perform your regular activities of daily living, like cooking and laundry	87
Go to social events, like parties	85.9
Go to big events, like a concert or a baseball game	71.2
Ability to go food shopping, run errands	65
Go to worship	27.1
Ability to live independently in your own place	25.4
Ability to drive, take the bus or subway	29.4

Current or Past Disability Payments

FORM OF SERVICES	%
Received some form of disability payments	28.8%
Received short-term disability from a job	11.9%
Received SSDI	10.2%
Received SSI	5.6%
Received long term disability from a job	4.5%
Received short-term disability from a private pay insurance	2.3%
Received long-term disability from a private pay insurance	1.7%
Listed "other" as a source	3.4%

Exposure or Referral to Vocational & Rehabilitation Services

Have you ever had any of these vocational services?	%
Received some form of vocational services	14.7%
On-the-job accommodations & assistive technology adaptations	6.3%
Job training services	5.1%
Job placement services	2.8%
Formal state vocational rehab services	2.8%
Vocational evaluation	1.7%
Services for restoration of functioning or adaptation of environment	1.7%
Job supports	1.7%

Evaluation of functional status

How often does your rheumatology provider ask you about your ability to perform the activities that are important to you at school/work and home	%
Every Visit	45.5%
Once in a while	24.2%
Never	29.2%

Referrals for Educational/Vocational Counseling

Has your Rheumatology provider referred you for educational or vocational counseling ?	%
Never been referred	92%
Yes have been referred	4%
Can't remember if I have been referred	4%

Exposure or Referral to Educational/vocational counselor

Have you ever worked with an educational counselor or a vocational counselor ?	%
No	81.8%
Yes	5.7%
Don't know what an educational or vocational counselor is	12.5%

Things We Learned ...

- + Much higher prevalence in racial/ethnic minority populations
- + Higher morbidity among racial/ethnic minority population
- + Unable to complete activities of daily living
- + Have difficulty maintaining full time employment
- + Providers are evaluating clients for functional status less than 50% of their visits
- + Very few were referred for educational/vocational services
- + Even if they were referred for educational/vocational services- few got services!

IMPLICATIONS

- Providers need to include evaluation of functional status in every visit
- Providers may not know enough to refer individuals for vocational rehab & educational support services
- Vocational and educational counselors may not know enough about Lupus and it's disabling impacts and the potential needs for individuals
- Individuals may not know how to reach out and/or access services & may not be aware of their own disabilities- such as cognitive deficits

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Directions for future research

- ❑ Need for more early identification and outreach to traditionally underserved and racial/ethnic minority individuals with Lupus
- ❑ The impact of race/ethnicity on vocational outcomes among persons with Lupus
- ❑ Need for more research on how these ed/voc services can improve outcomes for racial/ethnic minority individuals with Lupus

Education & Training

- Need for training and education of
 - Health care providers,
 - Individuals with Lupus,
 - Educators/schools,
 - Vocational rehab counselors

Limitations

- In 1st study too to measure functional status limited to basic skills
- In the 2nd study we did not ask race/ethnicity or length of time since diagnosis.
- We did not assess rheumatology providers or VAR providers' knowledge/ understanding of lupus and services

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