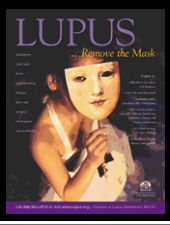
Adolescent Health & Adherence

PRESENTED BY:
L. NANDINI MOORTHY, MD, MBBS, MS, FAAP
SUSAN BRILL, MD, FSAHM, FAAP

American Academy of Pediatrics New Jersey Chapter

RUTGERS Robert Wood Johnson Medical School

Unmasking lupus in children- Health-related quality of life in children with lupus

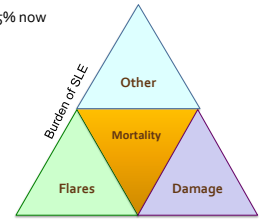


Lakshmi Nandini Moorthy MBBS (MD) MS
Associate Professor of Pediatrics, Chief – Division of Rheumatology, Bristol Myers Squibb Childrens Hospital- Robert Wood Johnson Medical School, Rutgers University, New Brunswick, NJ

Childhood onset SLE (cSLE)

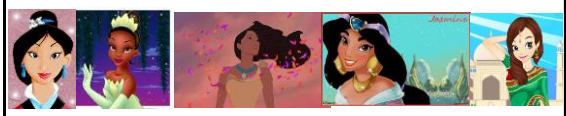
- SLE comprises 4.5% of US pediatric rheumatology clinic population
- Onset of disease before 18 years old is seen in approximately 15% of SLE patients.
- Among the larger published cSLE cohorts, the average age of diagnosis is 12 years(Brunner et al)
- 5-year survival: 64-87% in 1980s to >95% now
- 15- year survival rate: 76-85%

Tucker et al Lupus 2008, Stichweh et al Curr Opin Rheum 2004, Gonzales et al Lupus 2005, Ardoin et al Nat Clin Pract Rheumatol 2005, Borchers 2004, Ippolito 2008, Trager 2002, Uramoto 1999



cSLE prevalence

- Highest prevalence -Asian followed by African–American, Native American and Hispanic children (cohort >30 million children over a 5-year period) (Hiraki et al 2012; Medicaid data).
- Highest incidence of lupus nephritis was in Asian children > Native American>African American and Hispanic>White children.
- Asians have the highest prevalence of SLE and SLE nephritis and have most severe disease (Hiraki et al, Levy et al)



Ethnic variations in cSLE

- Children of European/White ethnicity/race have a lower incidence and prevalence of
  - SLE
  - lupus nephritis
  - have milder disease
  - may sustain less damage than other ethnicities/races

(Review by Silverman et al; Levy et al, Watson et al, Hiraki et al, Hersh et al)

Ethnic differences in pediatric SLE

Non-Caucasians were younger at diagnosis (12.6 vs 14.6 yrs; p = 0.007

Non-Caucasians had more renal disease (62% vs 45%; p = 0.01)

Blacks - increased prevalence of CNS disease vs. Asians (p = 0.108).

Hiraki et al 2009

Asians and S. Americans seemed to have a younger age of onset (Moorthy et al, 2012)

Dancing while playing chess, By Moorthy LN

Childhood onset versus adult onset SLE

Adult onset SLE vs. Childhood onset SLE

- Malar rash, lymphadenopathy, cytopenias, and nephritis have a greater prevalence in cSLE.

(Brunner et al, Mina et al Papdimitraki et al, Livingston et al) The Rheumatologist

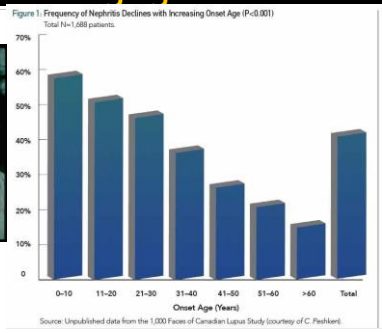
Levy et al, The Rheumatologist

Table 1: Cumulative Incidence of Common SLE Manifestations

	CSLE (%)	ASLE (%)
CONSTITUTIONAL – FEVER*	37–100	42–57
MALAR RASH	65–92	50–61
ORAL OR NASAL ULCERS*	14–49	14–42
PHOTOSENSITIVITY	35–50	41–56
ARTHRITIS	60–90	83–93
RENAL DISEASE*	50–80	31–65
NEUROPSYCHIATRIC SLE (ANY MANIFESTATION)	6–39	9–22
SEIZURES*	11–14	6–12
PSYCHOSIS	5–10	4–12
SEROSITIS	20–30	17–28
HEMOLYTIC ANEMIA	16–39	11–22
THROMBOCYTOPENIA*	15–37	14–38

*Manifestation has significantly greater prevalence in cSLE (odds ratio > 1 by meta-analysis)

Frequency of nephritis declines with increasing age of onset



Levy et al, The Rheumatologist

Mortality in childhood-onset SLE

Young adults with SLE: SMR 20 times higher than general population (vs. 2-5 fold in adults)

Accumulate disease damage more quickly; steroid related side effects; cognition; psychosocial issues

More aggressive course → increased exposure to immunosuppressive medications over a longer disease duration

More likely to meet ACR criteria for renal disease and have ESRD

(Brunner 2008, Tucker 1995, Tucker 2008, Hersh 2009, Hersh 2010)

Predictors for early mortality

Mean age at death 33 (childhood-onset; n=98) versus 52 years (n=859) (Hersh 2010)

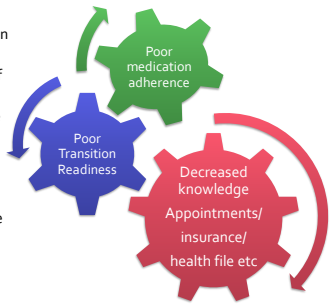
Childhood-onset SLE	Male sex
Education	Cardiovascular disease
ESRD	Medicare or Medicaid insurance

Hersh 2010

Poor self efficacy

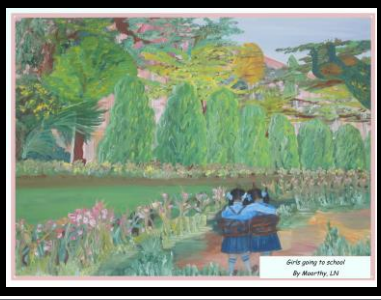
- 51 adolescents (Hersh et al)
  - moderate negative effect on their life
  - moderate understanding of their condition
  - were worried about change to adult providers
  - moderately prepared to manage on their own
  - large gaps in care with delayed presentation to the adult clinic of up to 33 months (mean 7 months)

Applebaum et al
Lawson et al



Can I take care of myself?

- In the 1st 6 months after diagnosis, teens with SLE report-
  - ~7 medications a day
  - ~5 pediatric rheumatology visits
  - laboratory testing on (up to) 8 separate days (Valente, Moorthy et al, 2012)
- 17% took 8 or more medications daily; 46% had 3-4 doctor visits per year and 34% had 8-12 doctor visits per year (Applebaum, 2013)



Health-related quality of life- measurement and development of SMILEY

Quality of life (QOL)

- "In the eye of the beholdee…" i.e. made up of personal values.

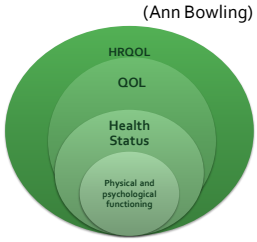
  (Re: QOL, Gill and Fenstein)
- "Global, dynamic and personal construct, encompassing physical, psychological and social domains."

  (RE: QOL, Farquhar)
- Should be considered in the context of the individual's goals and expectations

Health-related quality of life (HRQOL)

- HRQOL is defined as levels of mental, physical, role (work, parent etc.), and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being.

  (Ann Bowling)



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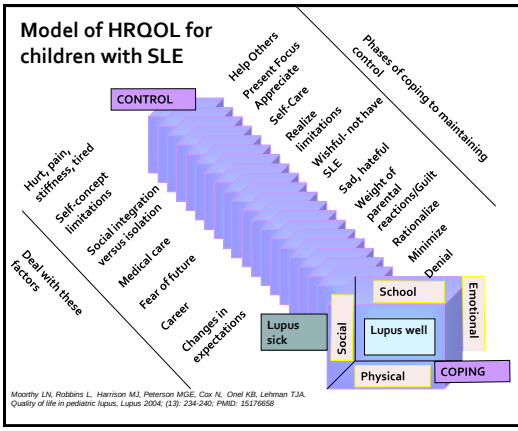
Exploring HRQOL of children with SLE – A qualitative study

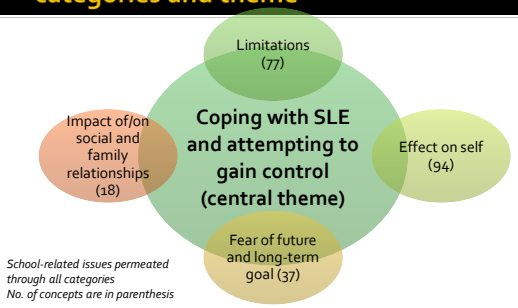
- We qualitatively explored how children (and parents) felt about having SLE
- That led to the development of SMILEY (Simple measure of impact of lupus erythematosus in youngsters)
- **QUOTES**
  - "I do greatly worry about the future…. passing on this disease to my offspring… Many times I feel I don't have as much time as everyone else."
  - "I can't do the stuff that kids of my age do… Everything in my life has changed."
  - "I wish I never had lupus in my life."

Model of HRQOL for children with SLE



Moorthy LN, Robbins L, Harrison MJ, Peterson MGE, Cox N, Onel KB, Lehman TJA. Quality of life in pediatric lupus, Lupus 2004; (13): 234-240; PMID: 15176858

Children's responses: overlapping categories and theme



School-related issues permeated through all categories
No. of concepts are in parenthesis

Moorthy LN, Robbins L, Harrison MJ, Peterson MGE, Cox N, Onel KB, Lehman TJA. Quality of life in pediatric lupus, Lupus 2004; (13): 234-240

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Parents' responses

Qualitative analysis	Parents' responses
Themes	**Parents made efforts to cope with their child having SLE**
	Parents appreciate and feel sad watching their children cope
Categories (no. of concepts)	Psychological (34)
	Accommodating disease (14)
	Shifting expectations (8)
	Social support (8)
	Worry/Fear of future (24)
	Medical care (23)

Moorthy LN, Robbins L, Harrison MJ, Peterson MGE, Cox N, Onel KB, Lehman TJA. Quality of life in pediatric lupus, Lupus 2004; (13): 234-240; PMID: 15176658

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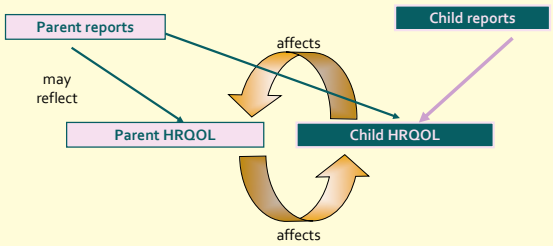
Child and parent reports influence each other but children's perspective is important



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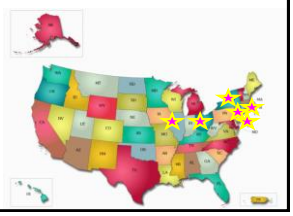
ORIGINAL ARTICLE

Multicenter Validation of a New Quality of Life Measure in Pediatric Lupus

L. NANDINI MOORTHY,[1] MARGARET G. E. PETERSON,[2] MARIA BARATELLI,[3] MELANIE J. HARRISON,[2] KAREN B. ONEL,[4] ELIZABETH C. CHALOM,[5] KATHLEEN HAINES,[6] PHILIP J. HASHKES,[7] AND THOMAS J. A. LEHMAN[2]

- 7 participating centers (n=86)
- Child and parent reports of SMILEY had:
  - Validity (face, construct, content, concurrent)
  - Internal consistency
  - Test-retest reliability



Sunflowers
With crayons, By Moorthy LN

HRQOL scores in pediatric SLE

In summary: HRQOL domain scores for PedsQL Generic and Rheumatology modules and SMILEY

Highest HRQOL: Daily activities, Treatment, Social

Lowest HRQOL: Worry, Burden of SLE, School, Emotional--requires examination

- SLE's effect on wellbeing is significant and is beyond physical and medical aspects of disease
- *Unclear why children and parents report high social scores- Is it a desire for acceptance?*

Perception of HRQOL: Parent versus child

Children
Have evolving needs and expectations
Are not miniature adults

Parents experience a greater awareness of disruption of child's life and anxiety about the future

Caregiver may experience a greater burden of SLE

Parent HRQOL scores were lower for several domains

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Sunflowers
With acrylic, By Moorthy LN

Relationship of HRQOL with disease and patient-related factors, especially school

Comments related to schoolwork

Subjects wrote the following comments (the quotes are not corrected for spelling or grammar).

Subject 1 (16-year-old girl): 'If I wasn't sick most of the time I'd be doing great in shcool, when i'm in school with my friends and teachers I feel great but when I'm absent I feel lost and hopeless.'

Subject 2 (18-year-old girl): 'Took longer to comprehend things and focus because of lupus'.

Moorthy LN, Peterson MGE, Hassett AL, Baratelli MJ, Lehman TJA . Impact of lupus on school attendance and performance. Lupus. 2010;19(5):620-7

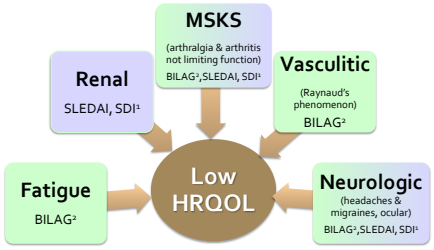
Relationship between school issues and HRQOL

Child-responses regarding school issues (descriptive questionnaire)	Spearman rank correlations with Child-report SMILEY
Satisfied with how the subject is doing in school	rho=0.3, p=0.1, n=41
Interested in schoolwork	rho=0.4, p=0.008, n=40
Difficulty remembering what was learned	rho=0.4, p=0.009, n=41
Difficulty concentrating on classes and schoolwork	rho=0.4, p=0.004, n=41

- Patients getting intravenous chemotherapy were absent on more school days ($p < 0.05$) compared with patients on oral medications
- Those who were absent on more school days had higher disease activity
- Child parent correlations were strongest for "missing school" (rho=0.6, p=0.001, n=25) and "feeling about going to school" (rho=0.7, p<0.001; 32)

Moorthy LN, Peterson MGE, Hassett AL, Baratelli MJ, Lehman TJA . Impact of lupus on school attendance and performance. Lupus. 2010;19(5):620-7

SLE (activity and damage) involvement of systems and HRQOL



1. Ruperto N, et al, Health-Related Quality of Life in Juvenile-Onset Systemic Lupus Erythematosus and its Relationship to Disease Activity and Damage, Arthritis Rheum 2004; 51 (3):458-464
2. Brunner et al. Health Related Quality of Life and Its Relationship to Patient Disease Course in Childhood-onset Systemic Lupus Erythematosus. J Rheumatol 2009; 36:7 (1498)

Relationship of HRQOL with disability, self-concept and other factors (Spearman's rho)

Constructs measured	SMILEY child rho (p) (n)	SMILEY parent rho (p) (n)
CHAQ disability index	0.6 (0.001) (86)	0.5 (0.001) (77)
Global quality of life of child	0.5 (0.01) (84)	0.6 (0.01 (78)
Days child was sick in bed or too ill to play	0.4 (0.001) (74)	0.4 (0.001) (69)
Days child needed someone to care for him/her	0.4 (0.001) (71)	0.5 (0.001) (66)
Interfered with parent's daily routine at work		0.4 (0.007) (56)
Interfered with parent's ability to concentrate at work		0.5 (0.001) (56)
Piers Harris Self Concept scale	0.5 (0.001) (81)	
***Better self-concept and higher socioeconomic scores correlated significantly with better HRQOL (PedsQL) (p<0.01)**		

Moorthy LN, Peterson MG, Baratelli M, Harrison MJ, Onel KB, Chalom EC, Haines K, Hashkes PJ, Lehman TJ. Multicenter validation of a new quality of life measure in pediatric lupus. Arthritis Rheum (Arthritis Care and Research) 2007; 57(7): 1165-73
Moorthy LN, Harrison MJ, Peterson MGE, Onel KB, Lehman TJA. Relationship of quality of life and physical function measures with disease activity in children with systemic lupus erythematosus, Lupus 2005; 14 (4): 280-287

HRQOL in pediatric SLE: Worldwide assessment

Pink water lilies
By Moorthy LN

Lupus (2010) 0, 1–11
http://lup.sagepub.com

PAPER

Relationship between health-related quality of life, disease activity and disease damage in a prospective international multicenter cohort of childhood onset systemic lupus erythematosus patients

N Moorthy[1], ME Baldino[2], V Kurra[1], D Puwar[1], A Llanos[2], MGE Peterson[3], AL Hassett[4], TJA Lehman[3] for the International SMILEY© Collaborative group
[1]Rutgers-Robert Wood Johnson Medical School, New Brunswick, USA; [2]Rutgers School of Public Health, Piscataway, USA; [3]Hospital for Special Surgery, New York, USA; and [4]University of Michigan, Department of Anesthesiology, USA

- Patients with cSLE and their parents completed HRQOL measures at enrollment and 5 follow-up visits.
- Physicians assessed disease activity and damage.
- The multinational cohort (n=467) had relatively low disease activity and damage.
- Patient and parent HRQOL scores were significantly correlated.

Table 1- patient characteristics

Table 1 Characteristics of cSLE patients at enrollment

Characteristics of cSLE patients (n)	n *(%)*
Gender (456)	
Male	72 (16)
Female	384 (84)
Race/ethnicity (441)	
Non-Hispanic White	157 (36)
Non-Hispanic Black	95 (22)
Hispanic	72 (16)
Asian/Pacific Islander/American Indian	77 (17)
Other (Blanco-Espana, Mulatto, Mixed Race, Pardo/Parda)	40 (9)

HRQOL scores

Table 2 HRQOL scale scores and CHAQ and comparison across continents at enrollment and follow-up

Scales	*Entire sample Mean ± SD (n)*	*North America Mean ± SD (n)*	*South America Mean ± SD (n)*	*Europe Mean ± SD (n)*	*Asia Mean ± SD (n)*
V1					
SMILEY – C[a]	67 ± 15 (452)	65 ± 14 (182)	67 ± 15 (106)	68 ± 16 (78)	72 ± 14 (86)
SMILEY – P[b]	64 ± 15 (431)	62 ± 15 (170)	65 ± 16 (110)	65 ± 15 (73)	68 ± 15 (78)
PedsQL – C	72 ± 17) (403)	70 ± 17 (179)	74 ± 17 (90)	71 ± 19 (54)	76 ± 14 (80)
PedsQL – P[a]	68 ± 21 (365)	64 ± 21 (163)	68 ± 20 (86)	67 ± 19 (51)	77 ± 18 (65)
CHAQ – C	0.3 ± 0.5 (231)	0.3 ± 0.4 (180)	0.2 ± 0.3 (12)	0.4 ± 0.6 (39)	*
CHAQ – P	0.3 ± 0.5 (337)	0.3 ± 0.5 (169)	0.2 ± 0.4 (86)	0.3 ± 0.6 (52)	0.2 ± 0.4 (30)
V2					
SMILEY – C[a]	68 ± 14 (293)	66 ± 13 (122)	67 ± 13 (83)	74 ± 14 (50)	71 ± 15 (38)
SMILEY – P[b]	66 ± 14 (267)	63 ± 15 (106)	65 ± 14 (83)	71 ± 13 (48)	72 ± 10 (30)
V3					
SMILEY – C	67 ± 15 (158)	66 ± 15 (79)	69 ± 14 (49)	71 ± 16 (20)	65 ± 16 (10)
SMILEY – P	66 ± 14 (135)	65 ± 14 (66)	66 ± 14 (49)	70 ± 14 (18)	68 ± 19 (2)

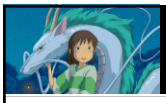
Visits up to 6 visits
Only first 3 show here
Asian and European patients had the highest HRQOL, while South and North American patients had lower HRQOL scores.

The relationship between HRQOL, disease activity and damage in a large prospective international cohort of cSLE.

- Renal, CNS, skin and musculoskeletal systems exhibited the highest levels of damage.
- **North and South American and Asian patients were more likely to have disease damage and activity scores** above median values, compared with Europeans.
- **Asians were more likely to use cyclophosphamide/ rituximab**.
- Female gender (p<0.01), high disease activity and damage, non-White ethnicity, and use of cyclophosphamide and/rituximab were related to lower HRQOL.

So how can we improve HRQOL in patients with cSLE?

Kitten in thought,
By,
Nandini Moorthy (oil pastels)



Coping strategies

Positive techniques (adaptive or constructive coping)

- Anticipation
- Social coping
- Meaning-focused coping
- Avoiding thoughts or circumstances that cause stress
- Nutrition, exercise, sleep contribute to stress management, relaxation techniques
- Humor

Negative techniques (maladaptive coping or non-coping)

- Dissociation
- Sensitization
- Anxious avoidance
- Escape (including self-medication)

Coping mechanisms

- Personal/family resources
- Avoidance and doing nothing about the situation
- appealing to a supernatural power
- Strong traditional values (different among different Asian communities)

(Hwang et al, Shek et al)
Perceived Social Support, Coping Styles, and Chinese Immigrants' Cardiovascular Responses to Stress, Lee et al 2012

Patients with SLE- a heterogenous population

Remarkable Diversity!!

- Major religions
- Major languages
- Dialects
- Range of cultural practices
- Different levels of preservation of cultural practices through 2nd and 3rd generations

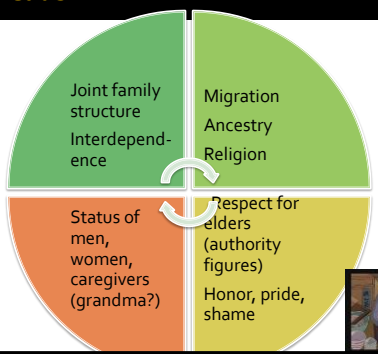
How to communicate with families

Mother and child, by Moorthy LN

What do you/can you assume?

- Family Structure ?
- Health behavior ?
  - Traditional medicine
  - Attitude towards western medicine
  - Trust?
- Dietary behavior?
- Religious behavior ?
- Acculturation/Migration?
- Socioeconomic status
- Taboos?

Family Structure: Some Common Threads



Factors to consider

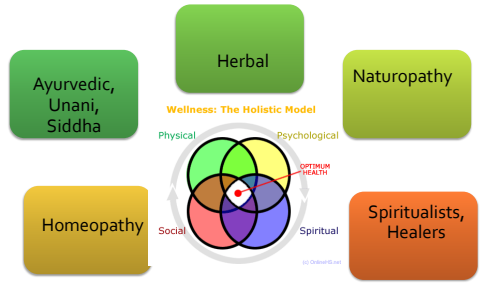
Psychological factors:
- Concept of self and relationship to family
- Developmental stage
- Adaptive capacity in own culture and other culture
- Immigration history
- Precipitating event
- Individual belief, understanding and reaction to one's own illness

Biological factors:
- Use of traditional/CAM medicines
- Attitude towards Western medicine
- Medical problems
- *Working with Asians, A guide to clinicians*

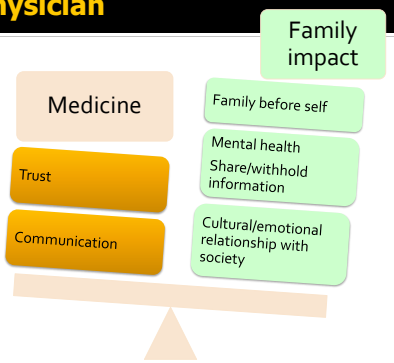
Environmental:
- Financial
- Knowledge of Western supports
- Transportation
- Housing

Psychosocial:
- Family structure
- Connection and participation in one's own community
- Acculturation
- Literacy/Education
- English proficiency

Practices around health that may be prevalent among patients



The balance you want to strike as a physician

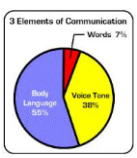


The mother said she wants …from the pediatric rheumatologist

- Wants complete information
- Clear outlining of steps
- Hope
- Leadership and connecting all the physicians
- Support
- Experienced physician

What can I do as a physician

- Respect
- Understand, listen and accept
- Child and family
- Open ended questions
- The most important part about communication is hearing what is not said (By Drucker)



Language and Communication

Large number of languages and dialects.

Non Verbal Communication
- Modesty is highly valued
- Same sex-care providers

Greetings

Direct eye contact from women to men may be limited.

Unfamiliar with the role of social workers and home care nurses.

Visits by these providers are not always acceptable

they prefer relying on help from family and friends

Lupus (2017) 0, 1–9
journals.sagepub.com/home/lup

PAPER

A North American perspective of content and quality of websites in the English language on childhood-onset lupus erythematosus

C Cutler[1], T Peng[2], J Stinson[3], L Tucker[4], A Boneparth[1], M Klein Gitelman[5] and L Nandini Moorthy[1]
[1]Department of Pediatrics, Rutgers Robert Wood Johnson Medical School, New Brunswick, NJ, USA; [2]Department of Pediatrics, Division of Allergy and Immunology, UCLA David Geffen School of Medicine, Los Angeles, CA, USA; [3]Child Health Evaluative Science, The Hospital for Sick Children, Peter Gilgan Centre for Research and Learning; Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, ON, Canada; [4]Division of Rheumatology, BC Children's Hospital, Vancouver, BC, Canada; and [5]Division of Rheumatology, Ann & Robert H. Lurie Children's Hospital of Chicago; Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

- Keywords relevant to SLE were generated
- Quality of information found was evaluated independently by 4 members using the DISCERN tool.
- Two pediatric rheumatologists assessed website accuracy and completeness.
- Readability of websites was determined
- Out of 2000 websites generated in the search, only 34 unique websites met inclusion criteria.
- Only nine websites of 34 had DISCERN scores above 50 (>66%, indicating greater quality) and
- were further assessed for completeness.
- Flesch-Kincaid grade level was 11+1

Conceptual framework

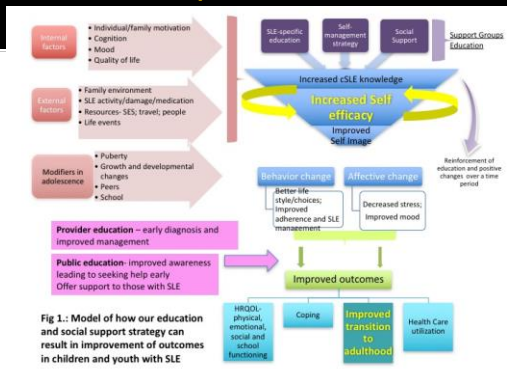


Fig 1.: Model of how our education and social support strategy can result in improvement of outcomes in children and youth with SLE

Pediatric Alliance for Lupus (PAL) Initiative wot

- PI, L. Nandini Moorthy, Office of Minority Health (with NJ AAP, July 2017- June 2018)
- Focused on **raising awareness and improving diagnosis and treatment of cSLE among racial and ethnic minorities** in three geographic locations in NJ– Trenton, Newark-Union, and Edison-New Brunswick
- Seeks to achieve early diagnosis, effective management, and improved health outcomes and health related quality of life for cSLE patients nationwide and in the target areas by **improving health literacy and enhancing the medical home** for cSLE patients.

Aim 1: Improve Health Literacy

- Needs assessment: Healthcare providers & Patients/caregivers
- Increase the number of online, age-appropriate, culturally sensitive resources readily available for children with cSLE and their caregivers (English, Spanish, Mandarin Chinese)
- Increase nationwide awareness and knowledge among HCPs, pediatric and adult rheumatologists of cSLE

Working with LFA, pediatric rheumatology consultants

Aim 2: Enhance the medical home for cSLE patients

- Increase the number of health care providers in the target areas providing an effective medical home, trained to identify, diagnose, manage and treat cSLE (given two webinars)
- Develop an ABP MOC Part 4 QI curriculum across the target areas to focus on early identification of cSLE
- Launch a stakeholder engagement campaign

- *Statewide Parent Advocacy Network*
- *Trenton Health Team*
- *Greater Newark Healthcare Coalition*
- *NJ Department of Health*
- *NJ Academy of Family Physicians*
- *South Asian Total Health Initiatives (SATHI)*

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Consuelo Modesto
Rolando Cimaz
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Claudia Saad Magalhães
Juliana Oliveira Sato
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Maria Odete Hilário
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Donato Rigante
Angelo Ravelli
Silvia Magni Manzoni
Luca Cantarini
Stephen Marks
Pavla Dolezalova
Bruno Ranchin
Pierre Quartier
Brigitte Bader-Meunier
Oscar Porras
Amparo Ibanez Estrella
Pilar Guarnizo Zuccardi
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EnriqueFaugier
Raúl Gutiérrez-Suárez
Amita Aggarwal
Arvind Chopra
Sharath Kumar
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Emma MacDermott
Laura Barinstein
Aimee Hersh
Andreas Reiff
Jorge Lopez
Christina Pelajo
Carol Lindsley
Suzie Wright
Philip J. Hashkes
Debora J. Bork
Nora Singer
Ingrid Tomanova-Soltys
Gina Montealegre Sanchez
Barbara Ostrov
Lisa Scalzi
Daniel Kingsbury
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Kim Adcock
Susan Massengill
Karen Onel
Sandy Hong

Consultants

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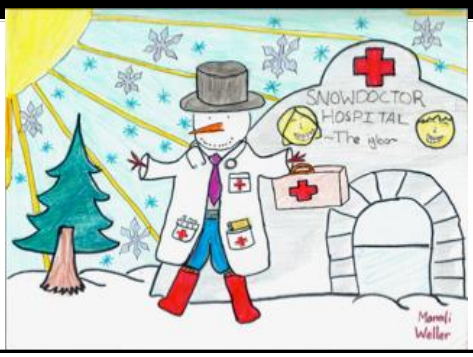


Susan Brill MD
Chief of Adolescent Medicine at Saint Peter's University Hospital
Clinical Associate Professor of Pediatrics
RWJ /Rutgers Medical School

How to get adolescents to take their medicine (even if they don't want to!) and how to help them transition to an adult specialty practice

Tasks of Adolescence

- Achieving independence from parents
- Adopting peer codes and lifestyles
- Accommodating and accepting new body image
- Establishing sexual and vocational identities

Early Adolescence-age 10-14 Psychological Development

- Less interest in parental activities
- Wide mood swings
- Concrete thinking,beginning of abstract reasoning, i.e. 'imaginary audience'
- Poor impulse control, with increase in risky behaviors

Mid-adolescence-age 14-16 Psychological Development

- More conflicts with parents, autonomy becomes important for most teens
- Intense involvement with peer group
- Better abstract thinking, but may regress under stress
- Feelings of omnipotence, immortality, leading to risk-taking behavior

Late adolescence age 17-21 Psychological Development

- Integration and appreciation of parental values
- More exploration of close relationships
- More realistic behavioral choices, ability to set limits
- Brain development, particularly around executive functioning, continues to age 25

Developmental model of compliance

- Kids age 10-14 think concretely
- Early teens focus most on immediate results of treatment/ side effects
- Focus on appearance/ outside effects of medication vs. inside/ (abstract)treatment benefits
- As teens get older can appeal to abstract reasoning, such as preventing future harm by taking prescribed medication

Early Adolescent Challenges

- Poor understanding of lupus and how it can affect health
- Concern about how medication can affect appearance such as increased acne and weight
- Difficulty understanding consequence of missing medicines and appointments

Mid-adolescent issues

- Increased tension and testing of limits in mid-adolescents can extend to health care providers
- "What if the doctors are wrong? What if I really don't have lupus? So what if I don't take my meds/ listen to the doctor? "
- Poor abstract reasoning makes discussion about compliance difficult

Later Adolescent Concerns

- Major task is to separate from parents and figure out place in society
- Patients with chronic illness often spend more time at home, less time socializing so may be delays in this area
- Going away from home (i.e. college) may be a major challenge for kids who need frequent medical care

Challenges for Adherence

Adherence: definitions

- The extent to which a patients behavior coincides with medical or health advice
- To include active voluntary collaborative involvement of patient and family in a mutually acceptable course of behavior
- Implies agreement in treatment among patient/ family /physician

Simple formula?

Adherence = Number of doses of medicine taken

Number of doses prescribed

More subtle ways patients can not adhere to recommendations

- Take a lower dose of medicine than prescribed
- Take too much of a medication
- Mistime doses
- Take less often than prescribed

How to monitor?

- Directly observed therapy (in office infusions)
- Pill counts (not always accurate)
- Monitoring of drug levels
- Assess clinical response
- Self report?
- Use of questionnaires

Barriers to adherence

- Demographic/ socioeconomic factors such as access to care/ stable insurance limits ability to full adherence
- Need to take a large number of pills
- Difficulty swallowing pills
- Limits on taking with/ without food
- Side effects

Condition related barriers

- Belief that medication does not work
- Belief that medication is no longer needed
- Difficulty taking medicine for health problems with no symptoms such as hypertension
- Testing to see if treatment is still needed
- **Teens will judge whether treatment is still worth it in their view**

Health Care setting barriers

- Frequent changes /loss of insurance creates difficulty in keeping appointments and maintaining relationship with same caregivers
- Challenges to patient/ family/ health care provider relationship
- Less time for visits
- Physician distraction using EMR**
- Lack of compassion or empathy of provider directly impacts adherence

Patient related Barriers

- Parental conflict may create a setting for poor adherence
- Parents may prematurely transfer responsibility to the teen before ready
- Previous bad experiences with health care system lead to lack of trust of providers
- Underlying depression/ substance use disorder often lead to poor adherence

How to improve adherence

- Keep medication and treatments simple
- Minimize # of doses/ day
- Optimize medication schedule around teen's day
- Limit or avoid disfiguring side effects if possible
- See patients frequently to reinforce treatment plan
- Screening for depression and substance use can identify these comorbidities

Improving adherence

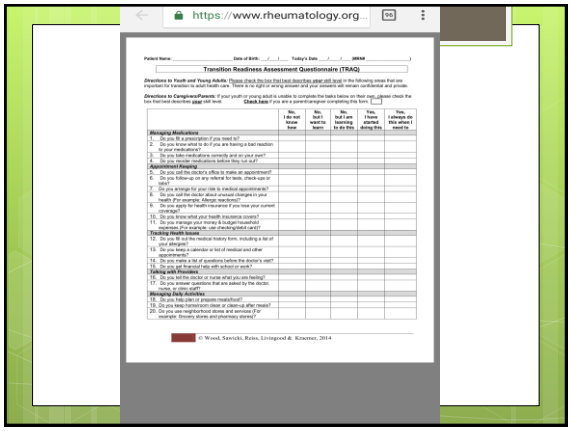
- Create trusting relationship between teen and provider
- Education regarding disease state/ consequences for missing medication crucial for teens to understand risks/ benefits
- Provide cues for medication/ pill boxes to organize pills/ cell phone alarm use
- Consider short term reward for taking medication appropriately

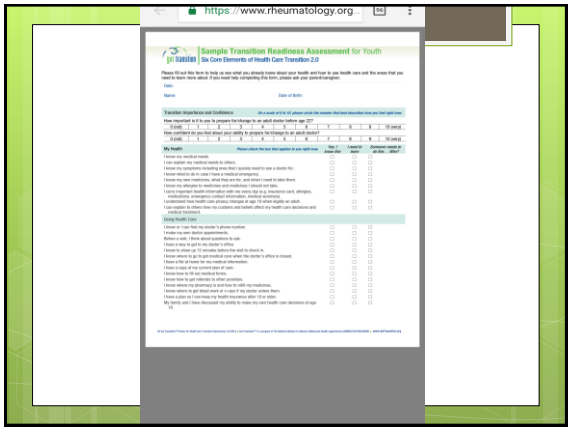
When is your patient ready to transition to an adult practice?

- Have a set office policy in place
- Discuss transition at least 1-2 years prior to age as per policy
- Create a referral list for adult rheumatologist and other care providers
- Allow for adequate time to set up appointments and provide needed information for new practice

Assessing readiness and maturity

- Use of questionnaires can assist provider in assessing readiness
- https://www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition provides wonderful resources for rheumatologists and providers
- Provide a detailed case summary for the patient esp. if medically complex





got transition.org Recommended Health Care Transition Timeline

- **AGE:12**
- **Make youth and family aware of transition policy**
- **AGE: 14**
- **Initiate health care transition planning**
- **AGE:16**
- **Prepare youth and parents for adult model of care and discuss transfer**
- **AGE:18**
- **Transition to adult model of care**
- **AGE: 18-22**
- **Transfer care to adult medical home and/or specialists with transfer package**
- **AGE 23-26**
- **Integrate young adults into adult care**

got transition: 6 Core Elements of Transition 2.0

- Transition Policy
- Transition Tracking and Monitoring
- Transition Readiness
- Transition Planning
- Transfer of Care
- Transfer Completion

Saying goodbye…

- Set a target date for last appointment
- Allow extra time if possible
- Assure patient has all necessary labs/ summaries
- Be available for questions/ concerns after appointment
- Be proud of guiding patient to good adult medical care!