

A Global View of Quality of Life in Lupus: Implications for Nursing

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Purpose

- To examine the physical, psychological, and social effects of Lupus (SLE) and their impact on quality of life in adults in culturally diverse settings
- Identify implications for nursing practice, research, and policy

Learning Objectives

- Identify factors associated with health-related quality of life (HRQOL) in adults with SLE
- Compare and contrast experience of HRQOL in adults with SLE from culturally diverse settings
- Identify implications for SLE care/research/policy

Significance of SLE

Approximately 1.5 million Americans and

At least 5 million globally

Disparities

Female to male ratio approximately 9:1 (Lupus
Foundation of America, 2017)

Global Burden

- Areas incompletely understood:
 - Incidence and prevalence
 - Population specific impact
 - Economic ramifications
 - Impact on HRQOL

Global Burden

- Variation attributable to factors such as:
 - Ethnic and geographic differences
 - Definition of SLE applied
 - Methods of case identification

(Carter, E. E., Barr, S. G., & Clarke, A. E., 2016)

HRQOL in SLE

- Common symptoms of SLE such as fatigue, depression, pain, sleep disturbances, and impairment in cognitive function negatively impact HRQOL (Gordon et al., 2013; Mirbagher et al., 2016)
- SLE and its treatment can significantly impact HRQOL (Carter et al., 2016; McElhone et al, 2010; Teh et al., 2009; Yazdany, 2011; Yee et al. 2009)

Methods

- Research articles using the LupusQoL© and its cultural adaptations
- Inclusion criteria: from 2007 to 2017; full text available; English language manuscript; in an academic journal; peer-reviewed

LupusQoL©

- Physical health (8 items)
- Pain (3 items)
- Planning (3 items)
- Intimate relations (2 items)
- Burden to others (3 items)
- Emotional health (6 items)
- Body image (5 items)
- Fatigue (4 items)

18 Studies Included in Review

- China (1)
- France (2*)
- Germany (*)
- Iran (2)
- Italy (1*)
- Mexico (2)
- Spain (*)
- Turkey (2)
- UK (4)
- USA (3)

*European study

Findings

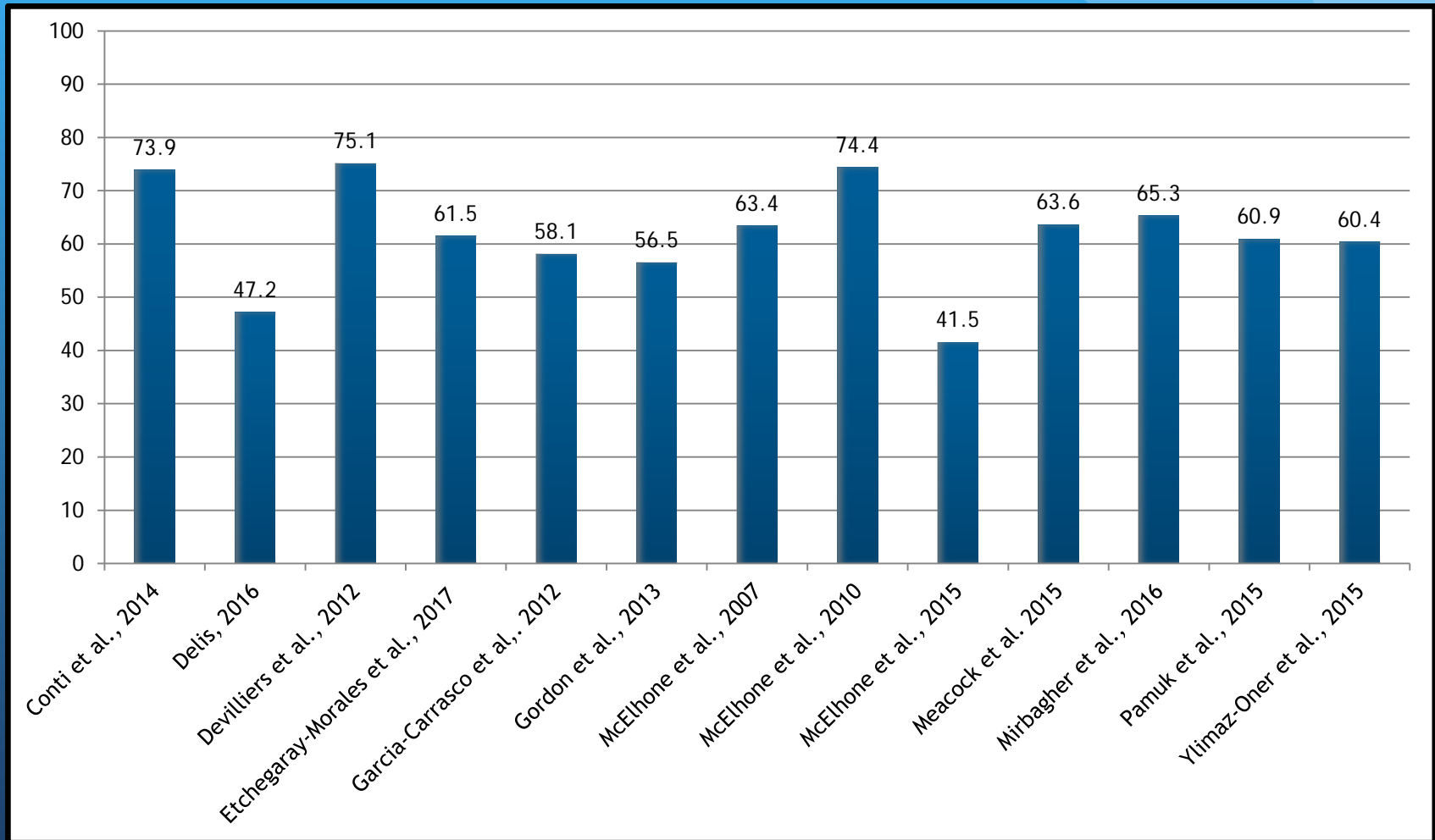
Demographics

- N = 298 (40 to 2070)
- Female 94.7% (87.9-100)
- Age 40.9 years (33.9-48.6)

Methodology

- 4 Prospective/
longitudinal
- 1 comparative/cross-sectional
- 13 cross-sectional

Mean Score of all Domains (61.7)



Factor Analysis/Domains

Study	Country	Factors	Most Affected	Least Affected
McElhone et al. (2007)	UK	8	Fatigue	Emotional Health
McElhone et al. (2010)	UK	NR	Fatigue	Body image
McElhone et al. (2014)	UK	NR	Physical health	NR
Meacock et al.(2015)	UK	NR	Fatigue	Emotional health

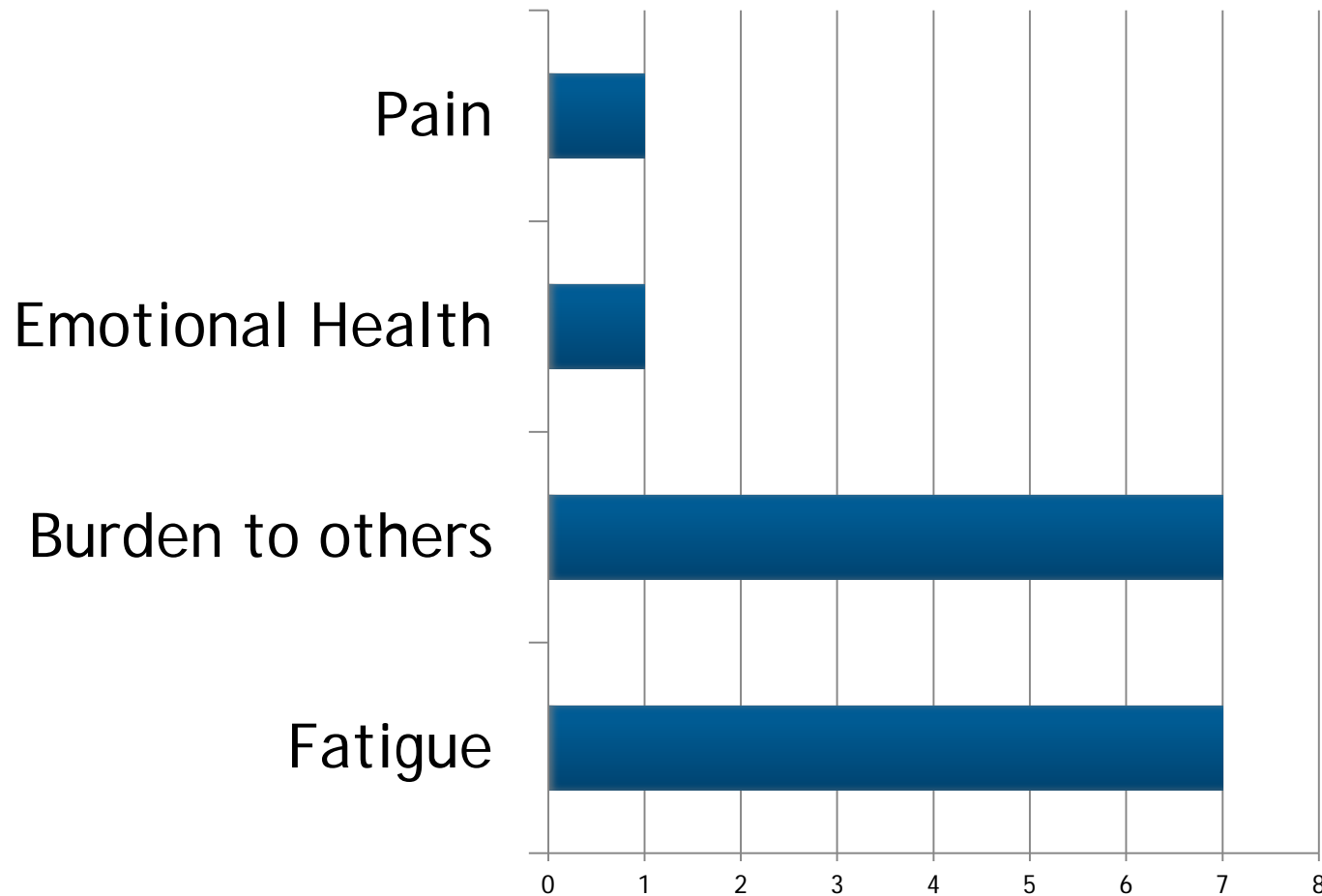
Study	Country	Factors	Most Affected	Least Affected
Conti et al. (2014)	Italy	5	Burden to others	Intimate relations
Devilliers et al. (2012)	France	2	Fatigue	Intimate relations
Devilliers et al. (2015)	France	NR	Fatigue	NR
Gordon et al. (2013)	Europe	NR	Burden to others	Intimate relations

Study	Country	Factors	Most Affected	Least Affected
Jolly et al. (2010)	US	5	NR	NR
Jolly et al. (2016)	US	NR	NR	NR
Delis (2016)	US	4	Fatigue	Emotional Health
Etchegaray-Morales et al. (2017)	Mexico	NR	Burden to others	Planning
Garcia-Carrasco et al. (2012)	Mexico	NR	Burden to others	Planning

Study	Country	Factors	Most Affected	Least Affected
Hosseini et al. (2014)	Iran	NR	NR	NR
Mirbagher et al. (2016)	Iran	NR	Emotional Health/ Burden to others	Planning/ Pain
Pamuk et al. (2015)	Turkey	5	Burden to others	Body Image
Wang et al. (2013)	China	6	NR	NR
Yilmaz-Oner et al. (2015)	Turkey	NR	Burden to others	Body Image

Most Affected Domains

Out of 14 Studies Reporting



Rankings

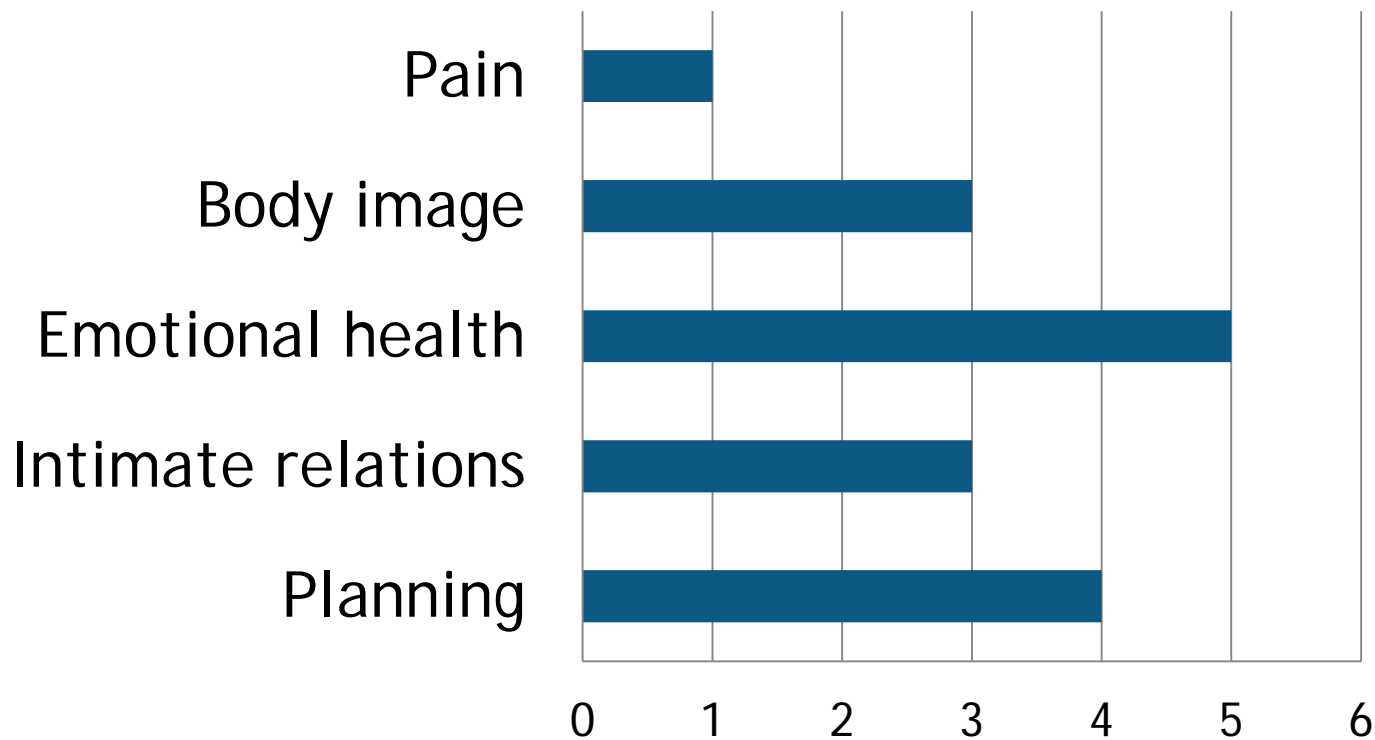
- Burden to others ranked #1-4 in all but one study (Pamuk et al., 2015)
- “I feel bad that I have made [my mother’s] life so difficult. Everyone [in my family] has had to change because of me.” (Miles, 2010)

Rankings

- Fatigue ranked #1-4 in all studies but 2 (Conti et al., 2014; Mirbagher et al., 2016)
- “Fatigue is the one symptom that affects my life the most. It...stops me doing things I want to do and it is the hardest to cope with.” (Connolly et al., 2014)

Least Affected Domains

Domain identified out of 12 Studies Reporting



Rankings

- Planning ranked in the bottom four in all but 3 studies (Conti et al., 2014; Delis, 2016; Gordon et al., 2013)
- Emotional health varied, with 7 studies ranking it #5-8 (UK & US studies) and 8 studies ranking it #1-4 (Iran, Turkey, France, Mexico studies)

Patterns Identified

- Feeling like a Burden to Others was ranked #1 in studies set in Mexico, Turkey, and Italy
- Body Image ranked #8 in studies set in Turkey
- Planning ranked #8 in studies set in Mexico
- Intimate Relations ranked #8 in European studies

Limitations

- English language only
- Not all studies reported factor analysis, domain and/or total LupusQoL scoring
- Limited age groups and cultures
- Amount of studies limits generalization of cultural-specific findings

Conclusions

- Negative impact of SLE on HRQOL in all populations studied
- HRQOL experiences vary
- Individuals' primary concern may be feeling like a Burden to Others
- Fatigue seriously impacts HRQOL
- Cultural differences in Lupus HRQOL may exist

Implications for Nursing Practice

- Asking about HRQOL gives voice to the individual with SLE
- Addressing HRQOL in addition to other measures of SLE activity can better inform the healthcare team and can allow for individualized plans of care

Implications for Policy and Research

- Incorporate HRQOL measure into practice for those with SLE
- Research opportunities in HRQOL in SLE include:
 - Age and gender diversity
 - More culturally diverse settings

Thank you

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References

Available through:

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Repository