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)

Corporate Translations, n.d.; McElhone et al., 2007
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

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Factors</th>
<th>Most Affected</th>
<th>Least Affected</th>
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<tbody>
<tr>
<td>McElhone et al. (2007)</td>
<td>UK</td>
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<td>Intimate relations</td>
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<tr>
<td>Delis (2016)</td>
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<td>Emotional Health</td>
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### Most Affected Domains

<table>
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<tr>
<th>Domain</th>
<th>Out of 14 Studies Reporting</th>
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<tr>
<td>Pain</td>
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<tr>
<td>Emotional Health</td>
<td>1</td>
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<tr>
<td>Burden to others</td>
<td>7</td>
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<tr>
<td>Fatigue</td>
<td>7</td>
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</tbody>
</table>

- Pain: 1 out of 14 studies reporting
- Emotional Health: 1 out of 14 studies reporting
- Burden to others: 7 out of 14 studies reporting
- Fatigue: 7 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

- Pain
- Body image
- Emotional health
- Intimate relations
- Planning

0 1 2 3 4 5 6
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:

Virginia Henderson Global Nursing e-Repository