

Assessing the Care Needs of People with Systemic  
Lupus Erythematosus

~

**Neta Margaret Moses BN, ADNE**

A thesis presented to the University of Newcastle in candidacy for the  
degree of Doctor of Philosophy

September 2009

*This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.*

*(signed)* \_\_\_\_\_

# Acknowledgements

This journey began with the assistance of two special women, each unknown to the other - Professor Margaret McEniery, who encouraged me to take the journey, and my co-supervisor, the late Professor Jill Cockburn who enabled my passage along the road.

A huge debt of gratitude goes to my supervisor Professor John Wiggers who managed to stay available and patient under a hectic and ever increasing schedule, while pointing the direction for my endeavours. He intuitively knew that I function best with less external pressure and had enough faith to sustain that approach.

In a class of his own has been my fellow collaborator on several papers, statistician Craig Nicholas. Craig facilitated my learning enormously by generously allowing me to question, argue and analyse until I arrived at a place of understanding. He has been the essence of a model teacher. Thank you Craig!

There is no way I could have accomplished this goal without the incredible help and support of my fellow PhD students especially in the early years. Each so willing to donate their time and skills in the midst of their own busy days. Ann Drew assisted me in the conduct of the focus groups and gave me unlimited tutorials on the vagaries of computers. Sheree Kable was always there with a shoulder to cry on and a wise word, and Claire Johnson was a never ending source of practical and technical explanations. Pauline

Chiarelli, Beth Fuller and Jo Gwynne added camaraderie to the day with all the pleasure that comes with that. Joan Maddox and I shared comforting understanding on a somewhat difficult lifestyle that we were both navigating individually, until her rapid and untimely passing.

Thank you to Debs Mainey and Karren Fergusson for their kind support, and to Kate Collins who has remained a cheerful and reliable presence for the entire duration. Katherine Honczar gracefully created the hard copy of the study questionnaire and the late Terese Alder was always and respectfully 'there'. Many thanks to Milena Luciani for her support, and to Peggy Ferrett and Debbie Smith who skilfully performed the data entry on which all else relies.

Dr Sue Outram has been a constant reassuring presence as Discipline Lead in latter times and knows just how to blend the professional with humanistic measure. Thank you Sue.

Thank you also to Professor Robert Clancy and Dr Glenn Reeves who provided expertise and 'thoughts' in the early days of the study's development, as well as Rachel Rossiter who readily placed herself as the liaison between myself and the many people with systemic lupus erythematosus in the upper and lower Hunter Valley of New South Wales.

My gratitude is incalculable to the staff and volunteers at the Lupus Association of NSW who somehow managed to assist me cheerfully at all times even though they had so many other projects to attend. In particular, Jeannette Rowe and the late Leslie McAllister

consistently went out of their way to enable the study to eventuate, while many Association members provided interesting and unanticipated feedback, serving to remind me how valuable an exercise this was from their standpoint.

Finally, I thank my daughter Aleta for allowing me to be with ‘it’ and not with ‘her’, and for providing her Information Technology expertise in the final stages of thesis preparation. She has taken much pride in my activities and that has kept me there without any qualms. My special friends have shown amazing faith that I would just get the job done and provided light relief for me along the way, while family members have demonstrated unlimited trust and interest in all related ventures. Hopefully, I can now spend more time with everyone and just be there for them.

It has been a unique and marvellous time-span of enormous learning and personal growth, and I thank the University of Newcastle for giving me that opportunity.

## Contents

List of Tables.....	viii
List of Figures .....	x
Synopsis .....	xii

## Chapter One

<b>Systemic lupus erythematosus, its characteristics, impact and need for care.....</b>	<b>1</b>
Systemic Lupus Erythematosus, its characteristics and impact.....	2
Aetiology .....	2
Disease activity.....	3
Diagnosis .....	5
Mortality .....	12
Health costs .....	13
Psychosocial impact of the disease .....	15
Meeting The Care Needs Of People With SLE .....	16
Quality of life.....	17
Satisfaction with care.....	19
Needs assessment .....	22
Defining needs.....	23
Measuring patient needs .....	23
Needs assessment in SLE .....	27
Conclusions .....	28
References .....	29

## Chapter Two

<b>Exploring the care and support needs of people with SLE.....</b>	<b>42</b>
Introduction .....	43
Method .....	53
Results .....	57
Discussion .....	77
Conclusions .....	81
References .....	83

## Chapter Three

<b>Development and psychometric analysis of the systemic lupus erythematosus needs questionnaire (SLENQ) .....</b>	<b>92</b>
Introduction .....	93
Method .....	94
Results .....	100
Discussion .....	108
References .....	114

## Chapter Four

<b>Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus .....</b>	<b>118</b>
Introduction .....	119
Method .....	120
Results .....	122
Discussion .....	134
References .....	140

## Chapter Five

<b>Persistence of unmet need for care among people with systemic lupus erythematosus: a longitudinal study .....</b>	<b>142</b>
--	------------

Introduction .....	143
Method .....	144
Results .....	151
Discussion .....	159
References .....	164
 <b>Chapter Six</b>	
<b>Conclusions and future directions .....</b>	<b>167</b>
Introduction .....	168
Burden and Impact of SLE .....	168
Measurement of Patient Needs .....	171
Prevalence of Need for care and support among people with SLE.....	172
Implications for research and practice.....	173
Conclusion.....	189
References .....	191
 <b>Appendices .....</b>	<b>201</b>



## List of Tables

Table 1.1 The American College of Rheumatology Criteria for Systemic Lupus Erythematosus 1982 ....	6
Table 1.2 Incidence and prevalence of SLE in Australia and other countries .....	10
Table 2.1 Categorization of dimensions of care .....	58
Table 3.1 Demographic and clinical characteristics of study participants .....	103
Table 3.2 Extracted factors .....	104
Table 3.3 Items without primary loading .....	104
Table 3.4 Factor loading by item for the seven domains .....	105
Table 3.5 Correlation of domains between the SF-36 and the SLENQ .....	106
Table 3.6 Reliability estimates for the factor scales of the SLENQ .....	106
Table 3.7 Ten highest loading variables by kappa value .....	107
Table 4.1 Demographic characteristics of participants who completed the SLENQ at Time 1 .....	124
Table 4.2 Significant correlates in the seven domains .....	125
Table 4.3 Proportion of participants with at least one need per domain rated 3, 4, 5 (Some Need) and 4, 5 (Moderate/High Need) .....	126
Table 4.4 Prevalence of unmet needs per domain .....	127
Table 5.1 Demographic characteristics of participants who completed the SLENQ at time 1 and time 2 .....	147
Table 5.2 Proportion of unmet need for top ten items – Time 1 and Time 2 .....	153

<b>Table 5.3</b>	<b>SLENQ items with significant reductions in proportion of participants reporting some need between Time 1 and 2 (<math>p &lt; 0.05</math>) .....</b>	<b>154</b>
<b>Table 5.4</b>	<b>Change in mean need domain scores over time between time 1 and time 2 .....</b>	<b>155</b>
<b>Table 5.5</b>	<b>Proportion of participants whose needs worsened, improved or stayed the same.....</b>	<b>156</b>
<b>Table 5.6</b>	<b>Correlation between symptom and need score (Time 2) .....</b>	<b>157</b>
<b>Table 5.7</b>	<b>Association between change in need score and need score over time.....</b>	<b>158</b>

## List of Figures

Figure 1.1	Needs assessments measure the gap between patients' current experience and their hopes.....	24
Figure 5.1	Change in mean domain scores over time.....	155

## **Publications and presentations associated with the project**

### **Publications**

Moses N, Wiggers J, Cockburn J, Nicholas C. Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. *Pat Educ Couns* 2005; 57: 30-38.

Moses N, Wiggers J, Nicholas C, Cockburn J. Development and psychometric analysis of the systemic lupus erythematosus needs questionnaire (SLENQ). *Qual Life Res* 2007; 16: 461-466.

Moses N, Wiggers J, Nicholas C. Persistence of unmet need for care among people with systemic lupus erythematosus: a longitudinal study. *Qual Life Res* 2008;17(6): 867-76.

Moses N. Assessing the unmet needs of people with systemic lupus erythematosus: Honoring patient self-report. [Commentary]. In: Ulrich CM, Bellinger KA, Eds. *Systemic Lupus Erythematosus Research Developments*. New York: Nova Science Publishers Inc, 2007: 9-15.

### **Presentations**

Moses N, Wiggers J, Nicholas C, Cockburn J. Assessing the unmet needs of people with systemic lupus erythematosus. Hunter Immunology Seminar, Newcastle, April 2005.

Moses N, Wiggers J, Nicholas C, Cockburn J. Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. European Association for Communication in Healthcare. Third International Conference, Basel Switzerland, September 2006.

## Synopsis

It has been said of systemic lupus erythematosus (SLE) that if a medical student thoroughly knew this disease they would know medicine, so diverse are the clinical manifestations of this disorder.<sup>1</sup> With improved diagnosis and treatments has come the challenge of how best to successfully manage and treat increasing numbers of people living considerably longer with this still incurable, but often debilitating condition. The need to identify appropriate treatment strategies for people with SLE has become an increasing priority in this context, as has the desirability of enhancing patient self-management in order to achieve better patient outcomes.

This thesis seeks to provide information regarding the particular care needs of people with SLE, information that can subsequently assist in the development of improved quality and appropriateness of care. The thesis explores the factors impacting on a patients' well-being through the development and psychometric analysis of a measure of the perceived unmet care needs of patients with SLE, through an examination of the prevalence of such care needs, and how they change over time.

The thesis comprises six chapters, with each being written as a distinct report in the style of a journal article. This facilitates the reading of the thesis but occasionally results in some repetition in some chapters. At the time of submission, four papers based on studies contained in this thesis have been published.

In order to fully comprehend the difficulties faced by people with SLE and their carers, and hence their need for care, an understanding of the characteristics and impacts of the disorder is essential. Chapter One traces medical recognition of SLE through the nineteenth and twentieth centuries and the subsequent evolution of treatment options. It examines the amalgam of potential symptomatology, and the subsequent complexity of issues that confronts the person with SLE on a daily basis, as well as the disease and cost burden involved in managing such a multifaceted disorder both for the patient and the community. The psychosocial impacts and need for care that are a corollary to this chronic health condition are explored, as are the mechanisms for their measurement via satisfaction with care and quality of life. The limitations of these measurement approaches are discussed, as are the potential benefits of adopting a needs assessment approach for measuring such impacts on need for care. The potential benefit of assessing and subsequently addressing patient unmet care needs as a means of improving satisfaction with health care, quality of life and ultimately care outcomes is discussed. The requisite criteria for determining a methodologically acceptable needs assessment instrument are explored. The conclusion is reached that the development of a disease specific needs assessment instrument is required as one means of addressing an existing gap in evidence regarding the extent of need for care among people with SLE.

Previous analyses have relied on single issue studies, literature reviews and health personnel report when describing the impact of, and need for care arising from a patients experience of SLE. Based on such studies, the second chapter describes some of the well

recognized areas of difficulties in the daily life of a SLE sufferer, and, through the reporting of the results of a focus group study, provides an understanding of need for, and gaps in care as personally reported by people with SLE. The study identified themes associated with obtaining current and easy to understand information, delivery of quality care by health care providers, family relationships and social interaction, financial and employment status, disease self-management, use of complementary therapies, and issues around identity, self-worth and mortality.

The results of the focus group study clearly suggested an unmet need for care across a wide range of care areas. The extent to which these expressed needs for care were reflective of the broader population of people with SLE remained unknown as no single study had previously reported the prevalence of such needs in a single study population. As an existing comprehensive and psychometrically validated SLE needs assessment instrument had not been reported, such an instrument was developed, known as the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ). The procedures involved and the outcomes of the development and psychometric evaluation of this measure are described in Chapter Three. The methodological criteria for needs assessment instruments (as outlined in Chapter One) were rigorously adhered to in the development of the instrument. The chapter details how face, content and construct validity were established and reliability of the instrument assessed utilizing tests of internal consistency and test-retest reliability. The questionnaire was pre- and pilot-tested before being administered in tandem with the MOS-SF-36 (to ascertain concurrent validity) in a study involving 386 members of the Lupus Association of New South Wales, listed as having a diagnosis of SLE.

Results indicated that the SLENQ provided a comprehensive measure of unmet needs in seven domains: psychological/spiritual/existential, health services, health information, physical, social, daily living, and employment/financial domains. The findings suggested that the SLENQ provides a reliable and valid index of the global needs of people with SLE.

Chapter Four presents the results of a study undertaken to determine the prevalence and correlates of need for care among people with SLE. The study was conducted with the same 386 support association members who were involved in the validity study described in Chapter Three. Each person was sent a needs questionnaire and asked to complete and return it within ten days. The study findings demonstrated high levels of need up to 81%, across all seven domains, with the highest unmet needs being measured in the physical (81%) and the psychological/spiritual/existential (72%) domains. Logistic regression models were conducted to identify correlates of levels of unmet need for each domain. It was found that participants who worked full time had less need in the daily living, health information and employment /financial domains than those on disability or sickness benefits. Higher unmet need in the physical and daily living domains correlated with increasing age, while people from an English speaking background or urban areas had higher unmet need in the psychological/spiritual/existential domains than those from a non-English speaking background or rural areas. The findings and their implications are discussed and suggestions are made regarding the regular utilization of the SLENQ and the provision of appropriate interventions to help ameliorate such need.



A longitudinal study of care needs is described in Chapter Five. The study was undertaken to determine the variability over time of unmet care needs of people with SLE. Overall, the level of unmet care needs for the majority of participants stayed the same, and more than three quarters of need items retained the same level of unmet need. Possible reasons for this pattern of results are discussed including seasonal change effects and the effect (or lack thereof) of interventions being sought or provided in the interim period. The results of the study suggest an unacceptable persistence of high levels of care needs not being met over the six month study period and that, as a consequence, there is an ongoing need to identify mechanisms for modifying care delivery so that the care needs of people with SLE are more effectively addressed.

Chapter Six concludes the thesis by providing a summary of findings from the various studies, and by discussing the implication of those findings for further research and clinical practice. Development of a short form SLENQ is recommended in order to enhance the feasibility and likelihood of the instrument being routinely used in clinical practice. Cross-cultural adaptation of the questionnaire is suggested, based on the marked variability in incidence and prevalence of SLE among cultural and ethnic groups. The need for such an adaptation for use among Aboriginal and Torres Strait Islander Australians is recommended.

The need and possible methods for the routine and regular application of the instrument by clinicians is discussed. Application of the instrument in this way has the potential to enhance clinician capacity to address the complex needs for care at each visit, and to

provide a means for clinician evaluation of the effectiveness of treatments and management plans provided. Various modes of administering the questionnaire in both clinical and home settings are explored including the utilization of a pen and paper version, employing a touch screen computer adaptation of the questionnaire, and the use of digital pen technology which integrates the pen and paper version with electronic data recording.

Limited evidence exists regarding possible clinical interventions designed to address both the provision of care and the enhancement of SLE patient outcomes in the areas of need identified in this thesis. Discussion of possible intervention is provided, drawing upon the results of needs assessment and needs intervention studies in other disease areas, most commonly cancer. This parallel evidence base suggests that consideration could be given to the development and testing of interventions such as a peer support program, provision of immediate feedback of patient self-report based on a needs assessment to the SLE specialist on each visit, and the use of a computerized telephone outreach system.

The chapter concludes with the view that the results of the various studies contained within the thesis demonstrate that SLE results in a broad range of negative physical and psychosocial impacts for the patient, that these impacts and a lack of care provision strategies designed to address them are very prevalent among people with SLE, and that such needs for care change little over a 6 month period. Further research into mechanisms for enhancing care delivery in these areas is therefore urgently needed.

## References

1. Wallace D. The Lupus Book. New York: Oxford University Press; 1995.