

Young People and Chronic Illness: A more responsive healthcare world

**A professional doctorate submitted in partial fulfilment of the
requirements for the degree of Doctor of Nursing**

**University of Technology, Sydney
2006**

Robyn Rosina

CERTIFICATE OF AUTHORSHIP/ORIGINALITY

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Candidate

Production Note:
Signature removed prior to publication.

ACKNOWLEDGEMENTS

I would like to acknowledge the following people who have given me so much support and valuable wisdom without which I would not have been able to complete my doctoral studies: my supervisor for her consistent patience, endurance and brilliance in supervision, my husband for his confidence in me, the young people with chronic illness and their families who have been the inspiration for my work, my co-supervisor in the final year of my studies who contributed a great deal to the important last stages of my work and finally to the editor who assisted in fine tuning the grammar and punctuation throughout my thesis. Without the constant encouragement and acumen of this team, my work would not have been possible.

.....

TABLE OF CONTENTS

Section	Page No
Abstract.....	x
Chapter 1:	
Young People and Chronic Illness: A more responsive healthcare world.....	1
Background.....	1
Introduction.....	3
Method Section:	4
Conceptual Design: Framework of this thesis.....	4
My Position in this Work.....	7
Situating the Work of this Thesis.....	7
Clinical Concerns and Clinical Context.....	7
Introduction to the Emerging NSW Health Policy Context For Chronic Illness.....	13
Focus of My Work.....	14
Reflective Analysis of the Practice Problem.....	15
Professional Doctorate in Nursing as Unique Opportunity.....	17
Thesis Development: Bringing together the specific literature, an empirical study and a theoretical analysis of the healthcare world.....	19
The Literature.....	19
The Empirical Study.....	20
The Theoretical Analysis.....	21
Theoretical Lens For This work.....	22
The chronosystem.....	24
The macrosystem.....	25
The exo and meso systems.....	25
The microsystem.....	26

Organisation of the Thesis.....	27
Chapter 2:	
Literature Review:	
Situating the work of the thesis in the literature.....	34
Background to the literature review.....	34
Linking the theoretical lens and the empirical findings to the selection of literature.....	34
Advances in medical science increasing survival.....	37
Increasing numbers of chronically ill young people.....	38
A seemingly unprepared adult healthcare system.....	39
Defining chronic illness.....	40
Links between treatment adherence and psychosocial factors.....	42
The experience of chronic illness and psychosocial functioning.....	43
The mental health of young people with chronic illness.....	45
A subgroup of chronically ill young people with poorer psychosocial functioning.....	47
Conclusion.....	47
Chapter 3:	
Treatment Adherence and Young People: An exploratory study of psychosocial wellbeing	49
Method Section:.....	51
Study design.....	51
Subjects.....	51
Measures.....	53
Procedure.....	55
Research Setting and Ethical Issues.....	55
Recruitment of Subjects.....	56
Results.....	57
Psychosocial Functioning.....	57
Treatment Adherence.....	59
Difficulties with Treatment Adherence and Concerns About Living with Chronic Illness.....	60
Discussion.....	63
Conclusion.....	65

Chapter 4:

Bronfenbrenner's Ecological Systems Theory.....	67
Introduction.....	67
Why I Used Bronfenbrenner's Ecological Systems Theory.....	67
Who Was Urie Bronfenbrenner and Where Did His Thinking Come From?.....	69
Understanding Ecological Systems Theory.....	71
The Chronosystem.....	72
The Macrosystem.....	74
The Exo and Meso Systems.....	75
The Microsystem.....	76
Criticisms of Bronfenbrenner's Ecological Systems Theory.....	79
Conclusion.....	80

Chapter 5:

The Chronosystem Level of Ecological Systems Theory.....	81
Introduction.....	81
The Chronosystem: Global healthcare reformations.....	82
New Chronosystems Bring New Healthcare Models.....	83
New Healthcare Models and the Impact on Nursing.....	83
Opportunities for Nurses in Change.....	84
Ethical Risks for Patients and the Response of Nursing.....	86
Opportunities for Nursing to Lead Change.....	89
Conclusion.....	96

Chapter 6:

The Macrosystem Level of Ecological Systems Theory:	
Nursing leadership in politics and policy.....	98
Introduction.....	98
The Macrosystem.....	100

The NSW healthcare system response to the increasing numbers of chronically ill.....	100
Outcome of reforms.....	104
New roles for nursing in NSW healthcare reforms.....	105
Nursing leadership and nursing reforms in NSW.....	108
Conclusion.....	109

Chapter 7:

The Exo and Meso Systems: Extending nursing practice scholarship.....	112
Introduction.....	112
The components of coping.....	119
1.Psychosocial developmental mastery.....	119
2.A sense of coherence.....	119
3.The trait of resilience.....	121
4.Locus of control.....	122
5.The utility of social and familial support.....	124
6.The strategy of normalising illness.....	130
7.The role of hope in adversity.....	132
Conclusion.....	133

Chapter 8:

The Microsystem Level of Ecological Systems Theory: Coping with chronic illness: a developmental perspective.....	135
Introduction.....	135
The psychosocial development of young people with chronic illness.....	137
1.Trust Versus Mistrust – Infancy (first year of life) and the sick infant.....	139
2.Autonomy Versus Shame and Doubt – (second year of life) and the sick toddler.....	142
Illustrating Responsive Nursing Practice: Case study of ‘Sophie’.....	143
3.Initiative Versus Guilt – Early childhood (preschool 3-5 years) and the sick preschool child.....	145
Illustrating responsive nursing practice: Case study of ‘Alice’.....	146
4.Industry Versus Inferiority – Middle and late childhood (6 years through to puberty) and the sick school-age-child.....	147

Illustrating responsive nursing practice: Case study of ‘David’.....	148
5.Identity Versus Identity Confusion – Adolescence (10-20 years) and the sick adolescent.....	150
Understanding psychosocial developmental discontinuity and the chronically ill adolescent.....	152
Parents and the psychosocial development of their chronically ill adolescent.....	154
Treatment adherence and the chronically ill adolescent.....	155
Psychosexual development, sexual health and reproduction.....	155
Risk taking behaviour	158
Illustrating responsive nursing practice: Case study of ‘Ellen’.....	160
6.Intimacy Versus Isolation – Early adulthood (20s and 30s) and the sick young adult.....	162
Illustrating responsive nursing practice: Case study of ‘Samantha’.....	163
Conclusion.....	166
Chapter 9:	
The Chronic Illness Healthcare World: Conceptualising nursing leadership at each level.....	168
Introduction.....	168
Nursing Leadership.....	170
Issues of power in nursing leadership: Barrier or strategy.....	170
Different types of leadership.....	171
Leadership and leadership activities that work.....	173
Clinical Nursing Leaders and Clinical Nursing Leadership.....	174
Characteristics of effective clinical leaders.....	174
The Role of a Clinical Leader and the Dimensions of Clinical Leadership.....	175
Further refining the definition and the role of clinical leaders.....	175
Clinical nursing leadership activities at each level of the chronic illness healthcare world.....	176
The Microsystem and clinical leadership activities.....	177

The exo and meso system and the interlinking role of clinical leadership activities.....	179
The macrosystem and clinical nursing leadership in policy and health care reform.....	181
The chronosystem level of the healthcare world and nursing clinical leadership activities.....	186
Conclusion.....	188
Chapter 10:	
Nursing Practice Scholarship and Clinical Nursing: A way forward to meet the challenges ahead.....	190
Introduction.....	190
Review of the Practice Concerns and Ways Forward to Optimise Psychosocial Outcomes.....	191
Summarising the Literature.....	192
Summarising the Empirical Study.....	193
The Theoretical Analysis of the Healthcare World.....	194
In Summary: Major findings and recommendations for each level of the healthcare world.....	196
The Chronosystem: The global healthcare world.....	197
Major Findings.....	197
Recommendations for Clinical Nurses.....	198
The Macrosystem: The NSW healthcare system.....	199
Major Findings.....	199
Recommendations for Clinical Nurses.....	201
The Exo and Meso Systems: Nursing scholarship linking the macrosystem to the microsystem.....	201
Major Findings.....	201
Recommendations for Clinical Nurses.....	203
The Microsystem: Nursing practice and the internal world of young people with chronic illness.....	203
Major Findings.....	203
Recommendations for Clinical Nurses.....	205

Clinical Nursing Leadership: Key to responsive reforms at each level of the healthcare world.....	206
Major Findings.....	206
Recommendations for Clinical Nurses.....	207
Conclusion.....	207
References.....	210
Appendix 1: Youth Self Report.....	228
Appendix 2: Young Adult Self Report.....	232
Appendix 3: ‘Managing Your Health’.....	236
Diagram 1: Bronfenbrenner’s ecological systems theory: theoretical framework for my work.....	22
Diagram 2: Conceptual framework for ecological systems theory.....	23
Diagram 3: Understanding ecological systems theory.....	71
Diagram 4: The chronosystem.....	81
Diagram 5: The macrosystem.....	99
Diagram 6: The exo and meso systems.....	113
Diagram 7: The microsystem.....	135
Diagram 8: The chronic illness healthcare world conceptualising nursing leadership at each level.....	168

ABSTRACT

There is extensive literature suggesting that, although most young people cope well and adjust to life with chronic illness, some young people develop poorer psychosocial health and functioning, and have an increased risk of psychopathology in adulthood. This area of concern to nurses working with these young people is poorly addressed in the literature, specifically, the literature about how young people with chronic illness are cared for from a psychosocial perspective, in an adult hospital, during the developmental period of adolescence. What literature does exist, focuses predominantly on the problems of improving treatment adherence, and provides little in the way of responsive service models or frameworks for nursing and interdisciplinary practice, to deal with underpinning psychosocial issues.

The aim of the work within this thesis is to extend knowledge about the psychosocial development and psychosocial health of young people with chronic illness. In particular, the focus is on how young people cope and adapt to living with chronic illness, and recommendations are made for clinical nurses to address the psychosocial needs of this group. The work of my professional doctorate emerged out of, is grounded within, clinical practice, and operates from the scope of experience of myself as a Registered Nurse, a Clinical Nurse Specialist, and as a Clinical Nurse Consultant.

The thesis has three components: first, a comprehensive analysis of the clinical situation that is at the centre of this thesis, and an associated literature review; second, an empirical research study focusing on one aspect of this complex situation; and a final, theoretical analysis of the healthcare world that young people with chronic illness experience, and of the professional lives of nurses. The clinical situation is presented as a reflective analysis of a clinical problem from multiple perspectives, and is followed by a review of relevant literature. The empirical study investigates the psychosocial functioning and treatment adherence of 85 young people aged 12-24 years in an adult hospital. The findings identify potential areas of difficulty in psychosocial functioning for some young people with chronic illness, suggesting that there is a subgroup facing significant challenges in coping with the effects of illness in their day-to-day lives. The third aspect, the theoretical component, builds upon the findings of the empirical study and examines the responsiveness of the healthcare world in relation to the needs of young people with chronic illness, and the place of nursing practice and clinical

leadership in addressing these needs. Clinical nursing leadership and clinical leadership activities are identified as being necessary at each level of this healthcare world. This leadership will ensure responsive nursing practice, the effective contribution of nursing skills within interdisciplinary teams and responsive policy reform, in order to optimise psychosocial outcomes for young people with chronic illness in an adult hospital.

Ecological Systems Theory (EST) provides the framework for the analysis of the healthcare world. The analysis revealed global dilemmas in how to sustain the provision of ethical, fiscally responsible, and clinically effective care to increasing numbers of chronically ill young people. The theoretical analysis facilitates the identification of potential ways that nursing can use a global perspective to plan services and to investigate the development of a coping framework for nursing interventions; and it highlights the crucial role of psychosocial developmental mastery in the formation of coping skills. The addition of Erikson's theory of psychosocial development complements EST by deepening the analysis of the internal world of the young people. The analysis draws on case studies to identify psychosocial risks, and points to several ways in which the clinical care of young people may facilitate developmental mastery; which I argue sits at the heart of coping and adaptation to illness.

.....