Young People and Chronic Illness: A more responsive healthcare world

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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.

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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.

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Chapter 1

Young People and Chronic Illness: A more responsive healthcare world

Background

Advances in medical science and nursing practice have increased the survival rates of many previously fatal diseases of childhood. The number of people affected by chronic illness is increasing rapidly in Australia and around the world (New South Wales Health Council, 2000). The western world will see chronic illness as the major burden in health care by 2020, contributing more than 60 per cent to the world's burden of disease (WHO, 2002). The numbers of young people with chronic illness in adolescence is increasing in all developed countries as larger numbers survive into their teens and twenties (Viner & Booy, 2005). Survival with chronic illness is reliant on intensive treatment regimes, and is heavily dependent on treatment adherence and expectations of high-level health care in the home. The aim of these treatment regimes is to extend life, prolong periods of remission, maximise symptom management and prevent long-term complications. The level of technological care now makes it possible for many people to remain at home, or closer to home, and have their illness treatment needs managed and monitored with fewer and shorter hospital admissions. The technology and intensity of these treatments can be extremely expensive in terms of the personal cost for the individual, their family, and the society.

Chronically ill people present frequently to healthcare services with a complex mix of medical, psychosocial and, for some, mental health problems (Combs-Orme, Helflinger, & Simpkins, 2002; Livneh, Lott, & Antonak, 2004). Healthcare systems in most western countries have evolved into two separate domains of service delivery - medical and mental healthcare. The medical model of care in hospitals is about the rapid resolution of acute symptoms, a focus on cure at all costs and discharge as soon as possible (Engel, 1977). There are fewer opportunities in the medical model of care to focus on possible co-morbidities and the prevention of future health problems. This model is now at odds with the diverse, chronic, complex and, increasingly, psychosocial healthcare needs of the growing numbers of ageing and chronically ill people dominating the healthcare system (Engel, 1977). The problem for nursing is that the frameworks of leadership, research, knowledge and practice development that shape the work of the profession have evolved largely out of the same medical model as the healthcare system (Antrobus & Kitson, 1999). This situation has created an increasing discrepancy between patient healthcare needs and the efficacy or capacity of nursing practice to address these needs, and it affects the ability of nursing leadership to influence appropriate reforms in policy, service delivery, and clinical practice development (Antrobus & Kitson, 1999).

The interaction and co-dependence of physical and psychosocial health states, in terms of health outcome, is emerging as a significant challenge. It is particularly significant in the context of both an unprepared healthcare system and a nursing profession attempting to bring about appropriate change (Vessey & Ben-Or, 2000). This is particularly evident among young people with chronic illness who are cared for in an adult hospital. Young people face a double challenge if they are forced to deal with the challenges of chronic illness during the potentially difficult and turbulent developmental period of adolescence. Unless the healthcare system in conjunction with the profession of nursing undertake responsive reforms, chronically ill young people are less likely to realise optimal bio-psychosocial health outcomes. Young people with poorer bio-psychosocial health may in fact become unnecessarily dependent on medical care and may be at increased risk of psychopathology in adulthood (Stuber, 1996). People with chronic illness, particularly with its episodic nature of symptoms, live in dual kingdoms of the well and the sick, with illness and wellness oscillating between the foreground and the background (Sontag, 1995). New understandings about the quality of developmental experiences and the psychosocial needs of this group call for a shift in thinking away from the burden and loss of illness toward notions of psychological health and wellbeing in the context of chronic illness and disability (Albrecht & Devlieger, 1999).

Policy reform and debate is largely out of touch with the contemporary needs of the chronically ill, particularly young people in adult hospitals. Current reform still evolves from historical notions about quality of life and medical outcomes, which have a persistent focus on treatment adherence, physical independence, and self-care (Sobel, 1995; Stewart, 2003). These indicators of health outcomes are fast becoming rhetoric, although they remain the outcomes of care, despite the situation where cure for all may not be possible and optimal symptom and complication management are the goals of care. Young people with chronic illness can remain physically well for long periods but are often reliant on parents and carers to support many physical and psychosocial needs (Stuber, 1996). Health outcomes for these young people are more about striving for career goals and a satisfying lifestyle despite the presence of illness and/or disability (Albrecht & Devlieger, 1999). The 'normal' trajectory of growth and development is often ill defined for young people with chronic illness. The markers of childhood and adolescence for chronically ill young people differ from well children and often last, well into the twenties; for some, it is impossible to meet the challenges of adulthood and independent living (Santrock, 1998).

Introduction

This thesis is predicated on the belief that the profession of nursing now needs to come forward with alternative healthcare policies, leadership strategies and responsive practice development to legitimately address the needs of the chronically ill into the future, including the specific needs of children and young people within adult hospitals, community and home contexts of health care. My view is that, for nursing, there are significant gaps and much work to be done but a great deal is reliant on the participation of nursing in service model development, policy debate and reform. With new appreciations of health outcomes and the clinical acumen of nursing participating in reform, clinical services may then begin to optimise bio-psychosocial health outcomes for the chronically ill, particularly young people in adult hospitals.

I had three primary aims to achieve throughout the course of my work. Firstly, I wanted to reflectively analyse a complex clinical problem and situation. Secondly, I wanted to extend knowledge about the psychosocial development and psychosocial health of young people with chronic illness in an adult hospital, particularly a subgroup that seemed to have more difficulties than others. As part of this aim, I wanted to explore whether there is a relationship between struggles with psychosocial health and treatment adherence; and, specifically, whether improving psychosocial health would lead to medical illness stability. My final aim was to undertake an analysis of the healthcare world of young people with chronic illness, containing nursing practice, and utilising a theoretical framework. I also wanted to establish new knowledge, by drawing from the literature and my clinical experience, about how young people cope and develop with chronic illness, and to put forward recommendations and frameworks that can inform practice in optimising psychosocial health outcomes for this group. The purpose of this work overall has been to understand the responsiveness of the healthcare world, in particular nursing scholarship, nursing practice, clinical leadership, and clinical leadership activities, in meeting the psychosocial needs of young people with chronic illness in an adult hospital. There were multiple areas that I could have been explored about how to improve health outcomes for this group. I decided that from my position as a clinical nurse the areas where I believed I could expand and improve the current level of knowledge, in ways to optimise health outcomes, were nursing scholarship, responsive frameworks for nursing practice and to identify clinical nursing leadership activities at each level of the healthcare world.

Method Section

Conceptual Design: Framework of this thesis

I decided at this point that, given the clinical problem and the complexity of the clinical context which was the focal point of my thesis, I would frame the work around a course of academic study. The Professional Doctorate in Nursing provided a unique opportunity to develop skills that would enable a clinical nurse such as myself to analyse clinical practice and the role of clinical leadership, in order to influence policy in ways that would optimise the efficacy of nursing practice within the health outcomes of young people with chronic illness in an adult hospital. The flexibility of approaches in scholarship and research, integral to the Professional Doctorate, provided an opportunity to explore a clinical problem and solutions in a number of different ways.

The thesis broadly has three components. First, my clinical reflections about young people with chronic illness in an adult hospital and a reflective analysis of a clinical problem followed by a literature review; second, a small empirical study to establish a greater understanding about the psychosocial health and the specific psychosocial problems of this group; lastly, analysis of the healthcare world of young people with chronic illness and the professional lives of nurses.

The first component of my thesis is an analysis of the complex clinical problem of young people with chronic illness being cared for in adult hospital and an associated literature review. The focus of this analysis is a subgroup of young people who are seemingly not coping with their illness or the impact of treatment on an adolescent lifestyle. This discrepancy in coping and the difficulties experienced by the families and clinicians in managing the increasingly complex medical and psychosocial needs of these young people was the impetus for my work.

The second component of my thesis is an empirical study, which emerged out of my clinical concerns, and was specifically designed to provide a deeper understanding of the psychosocial health of young people with chronic illness in an adult hospital and the specific psychosocial difficulties experienced by this group in coping with and adjusting to chronic illness. The study uses both quantitative and qualitative data to examine a series of research questions. The quantitative findings indicate that not only do some young people have poorer psychosocial health than others without chronic illness, but also that some have poorer psychosocial health than other young people with chronic illness. The qualitative findings identified numerous concerns about living with chronic illness and many psychosocial problems experienced by the young people. The qualitative findings also raised further unanswered questions about how young people cope with and adapt to chronic illness during adolescence and questioned the responsiveness of the adult hospital service model and nursing practice in meeting their needs.

The findings of the empirical study informed my decision to extend knowledge not only about the psychosocial development and psychosocial health of young people with chronic illness but also the ways in which nursing within the healthcare world can best meet their needs or influence responsive reform. Therefore, I decided to undertake a theoretical analysis for the third component utilising Bronfenbrenner's Ecological Systems Theory (EST) to organise the healthcare world into five levels; distal and proximal to the developing person. The bi-directional nature of EST provides opportunity for influences to impact on the lives of individuals at all levels of the framework (Erikson, 1968). In my use of the theory each level is represented by specific environments that contain events, resources, information and activities within the healthcare world that influence directly or indirectly the health outcomes of young people with chronic illness in an adult hospital.

The most distal level to the young person is the chronosystem. The chronosystem level contains issues and events pertaining to the global healthcare world that can potentially drive change and shape policy reforms at the next level, the macrosystem level. The macrosystem contains the New South Wales healthcare system, specifically the policy development activities that influence the health care of young people with chronic illness and related nursing practice development. The macrosystem is connected to the microsystem containing the young person by two interlinking systems, the exo and meso systems. The exo and meso systems connect the events, resources, information, and activities of the macrosystem to the microsystem. In my use of the theory these interlinking systems, the exo and meso systems, connect NSW health policy to frameworks for nursing practice and to the more immediate world of young people with chronic illness. The microsystem contains the interactions between the young person, the family and nursing practice, and the contribution of nursing practice within interdisciplinary teams to the health outcomes of young people with chronic illness. I decided to include a second framework for the analysis of the microsystem to provide a deeper understanding of the internal world of young people with chronic illness during the developmental period of adolescence. Bronfenbrenner's EST did not provide the level of detail across a series of developmental stages that I required for the analysis. Nor was there significant detail to enable the development of frameworks to support nursing practice development and thereby optimise psychosocial outcomes and coping skill development for this group. Therefore, I complemented the microsystem theoretical analysis and discussion with Erikson's theory of psychosocial development. I have used Erikson's theory of psychosocial development to illustrate the impact of chronic illness on psychosocial development. The primary tenet of Erikson's theory is that human development occurs across the lifespan in psychosocial developmental stages. This position is in contrast with earlier Freudian explanations that development occurred in psychosexual stages with the basic personality completed at five years of age. In Erikson's theory, overcoming a crisis, although a turning point of increased vulnerability, also enhances potential for developmental achievement and progression to the next stage (Erikson, 1968). The presence of chronic illness creates increased vulnerabilities for development achievement throughout childhood and adolescence with cumulative risks to psychosocial developmental achievement at each stage. Therefore, the analysis included the first six stages of development from infancy to young adulthood will be included in this discussion to highlight vulnerabilities and risk to development outcome contemporaneously. The discussion will use case studies from my clinical practice, to demonstrate the potential ways in which nursing practice can optimise psychosocial outcomes for this group. I argue that activities or the quality of activities within exo and meso systems have consequences and opportunities for other levels or systems across the framework that impact on the psychosocial development of children in positive and negative ways.

This thesis has a direct focus on the clinical world of nursing and the context of health care for young people with chronic illness. The outcomes of my work will assist nurses and teams of clinicians caring for young people with chronic illness. Therefore, it is important to be clear about the position of this work in the clinical world and the position of myself as researcher within the healthcare world. From this position I am seeking ways in which to optimise the efficacy of nursing practice, nursing skills and knowledge within interdisciplinary teams, and the contribution of nurses to policy reform, as well as to optimise the health outcomes of young people with chronic illness.

My Position in this Work

I began my doctoral studies as a Registered Nurse with a practice interest in adolescent health nursing. I was later appointed to the position of Clinical Nurse Specialist in Adolescent Chronic Illness Healthcare and then re-graded as the first Clinical Nurse Consultant in Chronic Illness Healthcare, or adolescent health more generally, within the area health service. The notion of a nursing speciality in Adolescent Chronic Illness Healthcare was indeed at the pioneering stage in the adult hospital, and within the larger area health service, where I worked.

As I identified the practice problems and decided on a course of study and skill development for myself, inherent in, the professional doctorate in nursing, I then had to establish my position in the work. Specifically, I had to decide what perspective I was looking from, and who were the professional group I intended to benefit from this work and the recommendations made. I have undertaken this work from the perspective and scope of experience of a Registered Nurse, a Clinical Nurse Specialist and a Clinical Nurse Consultant, providing nursing care to young people with chronic illness and their families during the developmental period of adolescence, as part of an interdisciplinary team within an adult hospital, operating within the NSW Healthcare system. Some aspects of my analysis and recommendations may appear a little naïve if viewed from a different perspective and/or nursing position and/or type of nursing acumen, within in the healthcare system. I emphasise that this work is about developing nursing practice scholarship, specifically about clinical knowledge development and establishing clinical leadership activities for a Registered Nurse, a Clinical Nurse Specialist and a Clinical Nurse Consultant to utilise in ways that can influence practice development, clinical service re-design, and policy reform to optimise psychosocial outcomes for young people with chronic illness. The work is not intended to provide a healthcare leadership framework or a policy analyst perspective or reform strategies beyond this reality.

Situating the Work of This thesis

Clinical Concerns and Clinical Context

The work of this thesis grew out of my practice concerns for a group of chronically ill young people in an adult hospital with illnesses such as cancer, cystic fibrosis, and major organ failure. The majority of these young people coped well with their illness and had good psychosocial health. I was, however, concerned about a subgroup of these young people, who clearly struggled not only with the physical impact of their illness but also with poorer psychosocial health.

This subgroup had urgent re-admissions to the hospital with frequent exacerbations of their illness. Exacerbations of illness related to treatment adherence problems were most often the reason for re-admissions to the hospital, despite multiple seemingly under-recognised psychosocial problems. Despite the life threatening nature of their illnesses, the young people were unable to manage the treatment regimens and lifestyle modifications required to stay well. These young people also had problems in coping with the impact of their illness on their lives, particularly where treatment adherence compromised a normal adolescent lifestyle.

Subsequent psychosocial assessment identified problems common to many young people but which were seemingly not addressed or not recognised by the medical model of assessment and treatment. On the other hand, the challenges of adolescence experienced by most young people may have been masked in some way by the presence of illness or manifested as struggles with treatment adherence. The assessments revealed problems which included the following: depression, loneliness, anxiety, suicidal thinking and behaviour, sexuality concerns, relationship problems, substance abuse, poor literacy, underemployment (despite the availability of suitable employment) and socio-economic struggles.

This emerging subgroup of young people struggling with chronic illness is in many respects a new patient group in our health system. The healthcare world has always seen sick and disabled children but many have not reached adolescence, if they did they were profoundly disabled and were not presented with the choices in life as were their contemporaries often living long into adulthood. This subgroup of young people includes survivors of what were once terminal diseases of childhood and, now express poorer psychosocial health. The number of young people in this subgroup is fewer in number when compared to those with chronic illness who seemingly expressed better psychosocial health. However, it is likely that these young people have longer and more frequent admissions, and are quite possibly much more expensive to treat. This subgroup, the focus of my practice concerns, has exposed ethical, economical, and moral dilemmas for the health system and the society, which need to be raised and addressed. As I thought and read more about the growing psychosocial concerns experienced by this group of young people, I came to realise that the numbers within this subgroup may increase or are perhaps already increasing as a subgroup within the adult chronically ill population, which indicates the importance of my work.

In my role as a clinical nurse consultant, I (together with a social worker) set up an adolescent psychosocial consultancy mode of care to provide education and advice to nursing staff and other clinicians caring for young people with chronic illness. The service also provided psychosocial and mental health assessments, psychosocial interventions, and the appropriate referral of young people admitted to hospital or seen in the outpatient clinics. Referrals to the service included young people who were not coping with their illness, who were in significant distress or experiencing problems with treatment adherence. As our service developed it became apparent we needed to know much more about how these young people coped with chronic illnesses and how to help them effectively. The model of health service delivery and nursing practice in the general adult hospital ward focused on the acute medical needs of patients. The shortening length of stay made it difficult for us to identify, monitor, or intervene with young people not coping with their illness or the impact of treatments. Many of the young people had multiple re-admissions, eventually longer admissions to the hospital and/or an increasing number of visits to the emergency department. The admissions or visits to the emergency department were often at a point of crisis and commonly involved an exacerbation of their illness, psychosocial concerns, and struggles with treatment adherence.

We were often confronted by a somewhat unexpected paradox in the lives of these young people. While medical science increased the likelihood that they would survive, the survivors at times struggled to find a reason to do so. This paradox created a level of resentment in some medical and nursing staff and, in some cases, adults in nearby beds. The distress experienced by parents, who felt compelled to support their children despite their difficult and concerning behaviours, often became a situation of conflict with the nurses. At times resentment in the ward was almost palpable towards an 'ungrateful' young person. Nurses who stepped into a more 'mothering' role to protect or reprimand their charges further complicated the resentment at times. There were multiple perspectives among the nurses on how to deal with defiant or difficult behaviour. This situation led commonly to differences of opinion within the nursing team and, not surprisingly, further 'difficult' behaviour from the young person. The somewhat strained nurse-patient-family relationships made for a challenging milieu for the adolescent consultancy service.

Referrals to the service, encouraged by nurses but activated by the medical staff, often came at the last minute when the relationships were most strained and difficult. These tense and sad situations at times negatively impacted on our service's credibility with the adult focused service. Many referrals to the service involved requests for advice on 'behaviour management' for non-compliant young people and distressed families. On many occasions, an unjustifiable deterioration in the young person's physical symptoms and their ability to self-care had prompted the referral to our service. The behaviours often included stubborn problems with treatment adherence, a resistance to following hospital protocols in day-to-day care and/or aggressive outbursts towards the self or others. The nurses caring for the young people were clearly distressed and saddened by their inability to deal with the conflict between the staff and/or the young people and their families. By the time, our service was called, initial contact with the young people and their families was certainly a challenge. We had to be careful not to become part of the problematic milieu when faced with overwhelming feelings of hopelessness and the sadness of the situation, whilst trying to gain the confidence of the nurses and build hope with the family. The numbers of 'difficult' young people and families were indeed fewer than those of young people who coped well, but the impact of the situation was certainly not to be underestimated across a number of domains. However, anecdotal evidence would indicate that the number of young people struggling with chronic illness and with their lives generally decreased with age, with indicators of adjustment emerging in their middle twenties, although there is little research to support this view. The emotional, economic, and social impacts of these difficulties were considerable for the young people, their families, the health staff, and hospital resources.

My clinical nursing experience had told me that the paediatric hospital milieu embodied a much more nurturing environment with an almost unswerving respectful understanding and patience for the distress of children and their families. I believed that the chronically ill child seemed to be regarded in the highest esteem by the hospital staff, the adults in the child's world, as well as in society in general. So, it was from this contrast, the ongoing conflict, and the inconsistency, that the questions for my work emerged. The contrast was that the changes became evident when the young person entered the adult health system. The conflict was generated by the presence of this 'problematic' group of young survivors, often seriously ill, cared for in adult services and seemingly causing distress and tensions throughout their admissions. The inconsistencies were that some young people with chronic illness achieved good psychosocial health and apparently remained well and adjusted to their illness over multiple admissions, while others, who had more and longer admissions, endured greater distress and had poorer bio-psychosocial health.

As part of my reflective practice, I began to try to understand the tension emerging between the patient, the family, the nurses, and the 'fall out' onto the surrounding patients in the ward area. I questioned whether a child with chronic illness, who was developmentally less autonomous, was more amenable to external control over day-to-day activities and emotional support in the paediatric context of care, where it would be much easier for parents and for health staff to feel more effective. However, the chronically ill young person during the developmental period of adolescence is struggling for and largely experimenting with self-control of decisions and their emotions. The distress of the hospital admission may well result in a regression in their psychosocial developmental milestones to a more confused state and poorer coping abilities. The situation can often be made worse with high patient: nurse ratios and less time available for the type of developmentally appropriate emotionally supportive approach the young person was more familiar with in the paediatric model of care. The medical staff appeared to notice the disturbance and supported the 'nurse-to-nurse' referral for advice (unusual and arguably a sign that medical staff were unable to offer solutions). The physically ill patient with 'behavioural problems' seemed to be well outside the skills of the medical staff who were becoming almost ambivalent and largely invisible in the management process. In some cases, a psychiatric assessment was sought but no mental illness was found and a diagnosis of 'an adjustment problem' was made with no further advice on management. On occasion, an antidepressant was ordered which was commonly refused by the young person or stopped after improvements in behaviour and coping were noted. My clinical experience told me that, given time and opportunity to experiment with self-control, the young people felt more in control of their world and the decisions being made, and in turn they were then better able to cope with the distress of the situation.

There are a number of factors that come together in the hospital ward milieu, for the young person, the family and for the nurses. For the young person the illness and its treatment may well interfere with their efforts to attain a satisfying, more independent adolescent lifestyle. The adult hospital often demands or works patients toward self-care and self-determination. However, there are limited opportunities for this outcome, even for adults, in the adult health system, except following discharge to the home environment. The young people, in many cases, have been ill since birth or childhood with their parents taking a lead role in care and the provision of emotional support. Nurses, working in the hospital medical model, are often proficient in the highly technical nature of chronic illness care but less competent and confident in understanding and working with emotions. The nurses may find it difficult to respond appropriately to the young people and their parents who are not coping with the illness, the treatment or simply being in hospital and out of control.

The hospital setting expects families either to be directed in their participation in health care or that parents hand over care completely to the health staff; whereas on discharge the families are expected to provide often highly technical care with fewer admissions and cope with significant burdens emotionally and financially (Wang & Barnard, 2004). The literature is convincing about the importance of parents in the care of children in health care (Fisher, 2001; Knafl & Deatrick, 2002; Meleski, 2002). The emotional impact on parents of relinquishing the care of chronically ill children remains poorly addressed in the healthcare relationship, particularly in the adult context of care. Kirk explored this aspect of nursing practice in a qualitative study interviewing parents of children and adolescents with complex needs (Kirk, 2001). The study included the responses of 23 mothers, 10 fathers, and 44 health professionals in an attempt to understand the tensions and contradictions that can ensue. Analysis of subject responses found that healthcare delivery was not subject to negotiation and that healthcare professionals often devalued the parental position in decision-making, despite parental expertise in understanding health care, their child's emotions and the management of family emotions (Kirk, 2001). This seemingly poor congruence in understanding emotions and role expectations is no doubt a big factor in the problematic milieu described in this study and my context of practice.

In my clinical milieu of the adult hospital, I believe that the nurses are not prepared in their education or in clinical practice to analyse or, indeed, to respond to the emotional work of coping with the lifelong implications associated with prolonged suffering. This situation has ramifications not only for their relationships with the young people and their families, but for themselves as health professionals. The ability to analyse and understand emotions and the role of emotions in nursing leadership has been identified in the literature as emotional intelligence (Cadman & Brewer, 2001; Vitello-Cicciu, 2002). A recent literature review explored the value of emotional intelligence for nursing practice (McQueen, 2004). The review found that the literature is convincing regarding the value of understanding emotions in the day-to-day work of nurses. However, the question of how to teach emotional intelligence in university curricula or in clinical practice remained unanswered in the review. Coaching nurses in managing their own emotions in negotiating the healthcare world and the role of emotions in coping with chronic illness may well need to become a critical part of nursing practice. Discussion about the emotional workload of young people and families with chronic illness is emerging in the chronic illness literature (Cadman & Brewer, 2001; McQueen, 2004). The area of emotional intelligence needs to become an important area of nursing research in the future.

I started experiencing a growing sense that healthcare reform, hence nursing practice development, for many years has persisted with reducing hospital admissions for the chronically ill and waiting times for surgery. This situation will over time shift chronic illness care into the community and the homes of patients and carers. It appears current healthcare debate and reform does not address the much-needed investment of resources into community healthcare; nor does it address the personal and social costs in supporting this growing context for chronic illness healthcare (Fulton, Penney, & Taft, 2001; Strawhacker, 2001). Given this gap in resources, the increasing concern for the numbers of chronically ill people and their emerging social and emotional struggles, it is surprising that current directions in healthcare reform remain unchallenged, particularly by nurses.

Introduction to the Emerging NSW Health Policy Context For Chronic Illness

The work presented in this thesis explores and theorises about the psychosocial health of young people with chronic illness, the chronic illness healthcare world, and the role nurses play or could play, in improving their experiences and patient outcomes. When this work began (or shortly before this work began) in 2000, the Department of Health in NSW had just appointed the NSW Healthcare Council and, following review by the Council, set an agenda to examine and enhance the responsiveness and adaptability of the healthcare system in NSW to meet the current and future needs of chronically ill people (New South Wales Health Council, 2000). The Council's report made recommendations to improve the coordination and management of healthcare services for the chronically ill, specifically to reduce urgent and unplanned admissions through the emergency department, to enhance funding and to increase consumer participation in health service reform (New South Wales Health Council, 2000). Whilst the report made a number of important recommendations, there was an absence in the discussion and recommendations about the psychosocial consequences of chronic illness or the ways in which the health system can respond. The ideas within this thesis and subsequent publications will expand the work of the Healthcare Council to include the psychosocial health needs of the chronically ill. The thesis extends this work in a series of chapters considering the psychosocial consequences of chronic illness for young people and their families by theorising and discussing the profound effects that healthcare systems, nursing leadership and practice have on the psychosocial health outcomes of the chronically ill. Recommendations for a way forward are made. This synergy, evolving from the work of the NSW Health Department, a review of the literature, and nursing leadership and practice, will be of significant value in addressing the increasing psychosocial needs of chronically ill people.

Focus of My Work

The work focuses on a subgroup of young people, in an adult hospital, with chronic illness who struggle coping both with the demand of their illness and its impact on their psychosocial health and functioning. It begins with an empirical study exploring the psychosocial health of young people with chronic illness to determine if there is any relationship to treatment adherence. There is a wealth of research identifying the problematic treatment adherence of young people without clinical significance in terms of more responsive interventions (Costello, Wong, & Nunn, 2004; Creedy & Crowe, 1996; Hill, 1999; Wysocki et al., 2003). Classic treatment adherence research recommends treatment regimen modifications and the importance of warning young people about possible long-term complications of poor adherence. This approach may ignore underlying problems in coping with illness. I argue that nurses need to understand much more about why some young people adjust well to illness and what markers indicate or perpetuate better coping. Further, I identify what factors can improve the healthcare milieu, specifically nursing practice, to optimise the psychosocial developmental experiences for young people with chronic illness. The important shift in research design that I am suggesting will contribute to a better understanding about coping and adjusting to illness as well as to the understanding of other specific developmental needs for young people with chronic illness. I will also question and explore if there is in fact any relationship between psychosocial wellbeing, coping, and treatment adherence.

Struggles with treatment adherence often mask underlying psychosocial concerns that remain unaddressed in the medical model of care that persists for the chronically ill, in paediatric and adult hospitals. This medical model remains problematic for nurses who might wish to change the model of care to support this group of young people. For this reason my work led me to contemplate how nurses might be able to influence the way in which health care for this group of young people was organised and delivered. In this thesis, I identify clinically relevant solutions to improve the ways in which the healthcare system can respond to the psychosocial consequences of chronic illness. I recognised early in my studies that, for responsive and sustainable change to occur at the clinical level of care, policy reform would need to occur at the policy level of the healthcare world. The reverse is also the case. My position or viewpoint as a clinical nurse consultant together with my nursing colleagues did not provide a way to see the entire healthcare world or the connections, factors and pathways that perpetuate change. As a result of this recognition, I decided that I needed to construct a way of viewing the healthcare world as a whole and then do an analysis to assist me and other nurses to understand how to bring about change. In this thesis the complex healthcare world and the role of nursing practice in the lives of young people with chronic illness is organised in a conceptual framework. Nurses can use this framework to guide their practice and encourage them to participate in leadership, policy, and practice development research to bring about responsive reforms.

Reflective Analysis of the Practice Problem

The work of my professional doctorate emerged out of, and is grounded within, clinical practice, clinical leadership activities, and how to use practice scholarship and clinical leadership to influence policy reform. The practice problems that led to my work were about a general absence of understanding within the adult healthcare environment of the psychosocial needs and difficulties experienced by young people with chronic illness and the impact of nursing practice on the psychosocial development of young people with chronic illness. I was also concerned about a subgroup of young people with chronic illness who had greater psychosocial difficulties and poor illness stability. The young people either had chronic illness since birth, or had been diagnosed during adolescence. What I was particularly interested in was how nursing practice could identify young people struggling with the psychosocial consequences of chronic illness, and what were the barriers within the healthcare world to responsive nursing practice, clinical leadership and clinical leadership activities to address the psychosocial needs of this group.

These young people were admitted to a large adult teaching hospital and spent many weeks, (and, for some of them, months) every year in adult hospital wards and/or outpatient clinics and day-care facilities. As was discussed earlier in this chapter, among all of the young people admitted to the hospital for the treatment of chronic illness, there appeared to be a core group that had numerous admissions and visits to the emergency department. As I explored the characteristics of this group more closely, the admissions seem to be related to frequent exacerbations of illness, often related to difficulties with treatment adherence and 'adjustment problems'. The other larger group of young people with chronic illness seemed to cope and adjust to their illness and treatment, with fewer admissions and less exacerbations of illness.

The problem for nursing practice was twofold. The first problem was that the direct care nurses, who worked within interdisciplinary teams providing highly technological medical and nursing care, were constantly confronted with a group of young people that struggled with life both in and out of hospital and would not comply with treatment regimes to maintain illness stability. The group were disruptive in the adult ward setting and were considered by many to be ungrateful for their expensive treatments. The young people often exhibited behaviour problems, some normal to adolescence, but not recognised in this light, and some young people presented with early features of mental illness, that also seemed to go unnoticed. The direct care nurses were not prepared with the skills to clinically assess, identify, manage, and/or refer youth health issues or mental health problems, within the context of a chronic illness.

The second problem was that the level of acuity of the presenting problems described here were not considered 'serious' enough for the medical officers to make a referral to a mental health service or youth counselling service. A referral from the Registered Nurse to a Clinical Nurse Consultant was also not acceptable in the medical model of care at this time unless approved by a medical officer. The other problem was that many referral intake systems for such services, within the hospital or the community, did not see these 'psychosocial' problems experienced by young people with chronic illness as a priority in a treatment-resource limited mental healthcare world. I came to the position that the only way forward would be to expand knowledge and enhance the existing nursing practice model with assessment skills and the involvement of the adolescent medical consultancy service at the hospital.

However, despite the presence of a newly developed adolescent medical consultancy service within the hospital, set up for specifically for young people with chronic illness experiencing developmental or illness related problems, the medical director of the service was not permitted to take direct referrals; many young people were not referred to the service as a matter of course, but more often at a point of high level distress and/or with the young person being either violent, refusing treatment or threatening self harm. It seemed that the hospital could see a problem, but had not quite thought through what the solution would require from the current healthcare service model. The solutions were not clear but would require policy reform and some considerations and adjustments made to the adult-focus model of care within the wards in order to address the psychosocial and developmental needs of young people with chronic illness. However, we, that is the adolescent health team, had seen this as a 'one step at a time' situation, and realised that a lot more knowledge and understanding was required about the problems experienced by the young people, as well as the practice and system problems, in order to propose and implement solutions.

Professional Doctorate in Nursing as Unique Opportunity

As I reflected on the practice and system problems evident within my practice, I considered potential ways in which I could deepen my understanding of the psychosocial health of young people with chronic illness and of the influence of policy reforms and nursing practice on health outcomes for this group. My aim was to contribute significantly to the generation of knowledge in the area, and ways in which practices and systems could be improved. As I read and learned more about professional doctorates in nursing it seemed that the course had been designed for clinical nurse leaders working in advanced nursing practice to engage in a program of supervised study and research. The journey of a practice doctorate allowed for the development of skills in the use of theory, a focus on leadership, exploration of different forms of scholarship, and the use of a range of research approaches to solve practice problems in order to bring about improvements in patient outcomes. The program of study offered at the University of Technology, Sydney is similar to the Doctorate of Nursing Practice, frequently referred to as a Professional Doctorate or Practice Doctorate, offered in the United Kingdom and the United States of America (Marion et al., 2003). A recent analysis of Professional Doctorates identified that the Professional Doctorate in Nursing offered in Australia was developed specifically for clinical leaders, such a nurse consultants, to acquire skills in multiple research methods to promote a patient focus agenda (Marion et al., 2003).

Practice doctorates integrate advanced practice, entrepreneurial clinical projects, interdisciplinary collaboration, health policy initiatives, and system thinking to develop solutions for complex practice problems that require clinical practice, policy and system redesign (Wall, Novak, & Wilkerson, 2005). The outcomes of a professional doctorate had synchronicity with the skills I required to address a complex practice problem and to bring about solutions that were multidimensional and linked to system change well beyond my scope of practice. These professional doctorate outcomes were as follows: the ability to

1. demonstrate advanced levels of clinical judgement and scholarship in nursing practice
2. critically analyse complex clinical situations, practice and policy development systems
3. evaluate and apply conceptual models, theories and research to advanced health care and to understand how to re-design these to optimise patient outcomes
4. analyse the social, economic, political and policy components of healthcare systems that affect care planning and delivery
5. understand clinical nursing leadership and assume a leadership role in the development of clinical practice models, health policy and standards of care to optimise patient outcomes
6. integrate professional values and ethical decision-making in advanced nursing practice and re-design models of care to meet the holistic needs of patients

Adapted from Veeser, 1999

These professional doctoral outcomes became a core component in the methodology and the journey of learning in my doctoral work and thesis development. I decided to first analyse the practice problem, from both clinical and systems perspectives with a comprehensive review of the literature. Secondly, I wished to conduct an empirical study to better understand the psychosocial health and problems for this group, and finally to undertake a theoretical analysis of the healthcare world, containing nursing practice, to expand knowledge, find solutions and make recommendations to influence interventions, healthcare model re-design and policy reform, to optimise psychosocial outcomes for this group.

Thesis Development: Bringing together the specific literature, an empirical study and a theoretical analysis of the healthcare world

The Literature

The quantity of literature related to chronic illness is enormous with many hundreds of thousands of articles, with diverse methodologies and perspectives. Therefore, I decided to provide a systematic review of the available literature across various domains of relevance to my thesis. What I was particularly looking for was literature, from both theoretical and research perspectives, to provide a greater understanding about how young people coped and adapted to chronic illness and relevant frameworks for responsive nursing practice and clinical leadership activities to influence reform. The group of young people included those with chronic illness since birth and those diagnosed with chronic illness during adolescence. More specifically I was looking for papers, both research and theoretical, that provided a greater understanding about how the healthcare system, containing nursing practice, managed the psychosocial developmental needs of young people with chronic illness in an adult hospital.

The review of the literature found that most young people adapt to living a chronic illness with few problems. However, there was some evidence to support my clinical concerns that some young people do not cope well, and struggled not only with their illness, but also the impact of the illness and its treatment, on adolescent development. What the literature did not answer was what the specific problems were for young people with chronic illness in an adult hospital. Also, there were no answers about what would be required in terms of frameworks for nursing practice and clinical leadership activities to identify and address the needs of this group and how to influence policy reform to optimise psychosocial health outcomes in an adult hospital setting? Following an extensive search of the literature over the years of my study, I have not found specific articles addressing these areas of study and therefore I had to broaden my examination of the literature.

Throughout the chapters of my thesis, I have selected literature specifically related to the specific components of the theory under discussion within each chapter. Further, I have identified areas of the literature relevant to the experience of young people with chronic illness and nursing practice, in adult hospitals that require further development. In particular, specific areas where little information is available and I have I have therefore undertaken to contribute to, within my thesis. I provide further information about the literature I have selected in the introduction to each chapter.

The Empirical Study

Given the questions that had remained unanswered following the literature review, I decided to undertake a quantitative and qualitative study to understand what the psychosocial health, functioning, and problems of young people with chronic illness were in an adult hospital. I also wanted to understand if there was any link between treatment adherence problems and psychosocial struggles for this group. The research questions were as follows:

1. Is the psychosocial health of young people with chronic illness different from those without chronic illness?
2. What problems do young people with chronic illness have with treatment adherence?
3. What concerns do young people with chronic illness have with other aspects of their lives?
4. Is there a relationship between psychosocial functioning and difficulties with treatment adherence?

Following consultation with adolescent health experts and my supervisors, I decided to use two instruments to understand the emotional and behaviour functioning of young people with chronic illness and their specific problems with treatment adherence. Two instruments were used firstly, Thomas Achenbach's Youth Health and Young Adult Self Report instruments, according to age (see appendix 1 and 2) and secondly, a questionnaire, specifically developed for this study, "Managing Your Health" (see appendix 3). The second questionnaire engaged both quantitative and qualitative strategies to understand more about the struggles of this group with both treatment adherence and general management of their lives with a chronic illness.

The study showed that young people with chronic illness most likely have an increased vulnerability to poorer psychosocial functioning compared to their peers without chronic illness. The results indicated that young people with poorer psychosocial health also had difficulties with treatment adherence, particularly in the young adult group. However, many young people in the study had multiple psychosocial concerns despite having seemingly no difficulties with treatment adherence. Many of the young people identified in the study as having multiple psychosocial problems were the same young people with frequent admissions to hospital, but they were not identified as having psychosocial difficulties or for some, mental health problems, beyond struggles with treatment adherence and adjustment problems. The psychosocial functioning and specific problems identified in the young people in the study, particular the discrepancy in coping across the groups, underpinned the question about the responsiveness of the healthcare system, containing nursing practice and leadership activities, for the theoretical analysis component of this thesis. At the close of the study, I came to the position that physical and psychosocial health outcomes for young people with chronic illness, during the developmental period of adolescence, were most likely linked. The question for the theoretical analysis was what sorts of nursing practice, service model re-design and policy reform would be required to optimise outcomes for this group in an adult hospital. Further what role would nursing have in these sorts of reforms?

The Theoretical Analysis

The findings of this empirical study directed my thinking outwards towards the healthcare system, more specifically asking what impact did the interventions, nursing and interdisciplinary, service model design and policy have on the psychosocial outcomes for this group. Further, I wondered what sorts of clinical re-design and policy reform could optimise both physical and psychosocial outcomes simultaneously and what role could nursing have in this work? I decided that to answer these questions and to establish new knowledge about how young people cope with chronic illness, during the developmental period of adolescence identified in my literature review, I would need to undertake a theoretical analysis of the healthcare world of young people with chronic illness. This theoretical analysis became the third component of my work. The entire thesis is about using practice analysis and scholarship to identify specific clinical leadership activities to establish new knowledge to influence both policy reform and clinical service models re-design in ways to optimise the psychosocial outcomes for young people with chronic illness in adult hospitals.

The enormity of the task led me to organise the analysis into two worlds; the internal world of a young person with chronic illness and the interplay between this internal world and nursing practice, and the external world of the healthcare system, containing nursing practice. Secondly, I decided I required a theoretical framework to organise these two worlds in ways that provide contexts for analysis and discussion. This work would then make recommendations for nursing practice and clinical leadership activities to influence clinical service re-design and policy reform within and across contexts.

The three components of my work: the clinical problem analysis and literature review, the empirical study and the theoretical analysis, come together as a whole to do three things. Firstly, to meet the learning outcomes of a professional doctorate in nursing. Secondly, to establish new knowledge about how young people cope and adjust to the impact of chronic illness on their psychosocial health and development during adolescence, and to make recommendations for responsive nursing practice, service models and policy development. Finally, to create a systematic approach to the identification and analysis of other complex practice problems, and using the literature and clinical expertise, to identify strategies that clinical nurses can use to bring about practice change and health system re-design, to optimise outcomes for patients.

<u>Theoretical Lens for This Work</u>

<u>Diagram 1</u>

Bronfenbrenner's Ecological Systems Theory

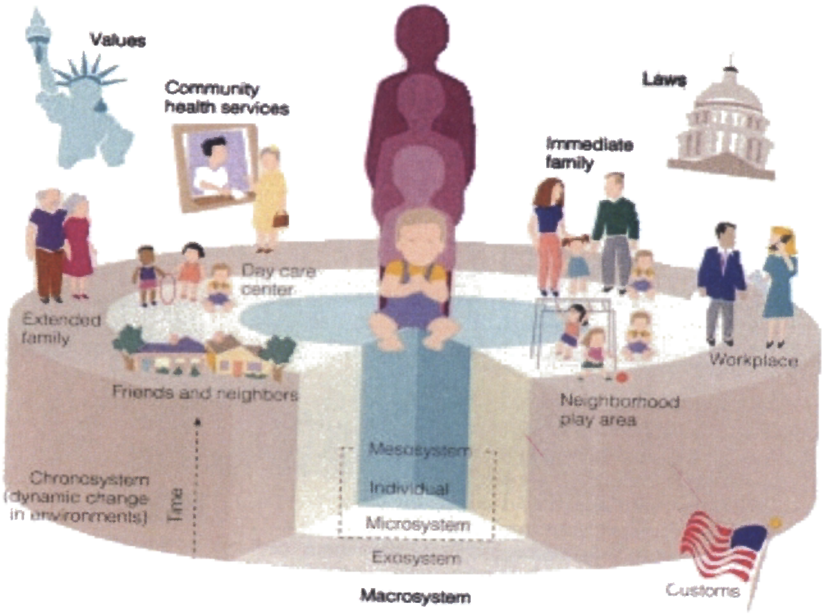
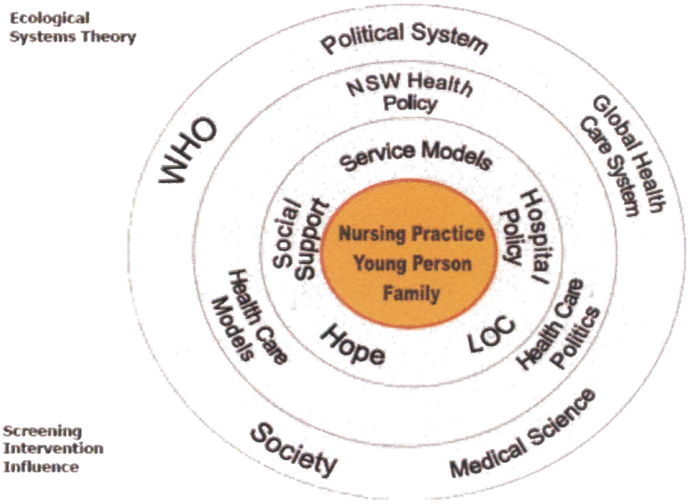


Diagram 2

Conceptual Framework of EST

- Chronosystem (outer most)
- Macrosystem
- Meso & Exo systems
- Microsystem (inner most)



I have used Bronfenbrenner's Ecological Systems Theory (EST) in my work to organise the complex healthcare world of the young person with chronic illness into a series of environments. Bronfenbrenner argues that human development is an outcome of interactions between the individual and their environment (see diagram 1) (Bronfenbrenner, 1971). The central tenet of EST is that the developmental outcome of individuals, particularly those facing adversity, can be influenced by both internal factors and external factors. These factors can potentially be manipulated within the environments to enhance or impede psychosocial outcomes for the individual. The theory is used widely in the literature for its greatest strength, that of organising complex systems in a logical framework. The framework then provides the opportunity to analyse phenomena within and across each of the environments.

Chapter 4 describes and analyses EST in more detail but what I would like to add here, in this discussion, is how I have used the theoretical lens of EST to select and interpret the variables under analysis and discussion at each level of my conceptual framework (see diagram 2).

The phenomenon under discussion within this thesis is the psychosocial outcome of young people with chronic illness in an adult hospital. The research question that has framed my research is, why or what factors cause some young people to cope and adapt better to chronic illness, resulting in a better psychosocial outcomes whilst other young people with chronic illness, with seemingly similar environments, achieve poorer psychosocial outcomes. Further, how do nurses identify young people struggling with, both their illness and the impact of treatment on adolescent psychosocial development? The overall aim of my work has been to extend the existing knowledge in the chronic illness literature to provide a deeper understanding of the psychosocial development of, and problems for, young people with chronic illness and how to improve the developmental experiences of this group in an adult hospital. This group spend long periods during their childhood and adolescence in hospital and accessing hospital services. It is reasonable to argue that healthcare interventions have a mediating role in the psychosocial outcomes for this group.

I have worked from the premise that young people with chronic illness still have the capacity to develop coping skills, normally achieved in psychosocial development mastery, but frequently these are delayed or interrupted by the presence of chronic illness and treatments. However I have argued that despite the presence of chronic illness, specific adjustments to the external world can be made, in terms of nursing and interdisciplinary interventions, to support the development of coping skills and thereby optimise psychosocial outcomes for this group.

Ecological Systems theory organises the healthcare world into five environmental contexts with the young person as its centre, with equal focus on the individual and the environments (see diagram 1 above). I have conceptualised these environments as a conceptual framework of the healthcare world (see diagram 2 above). Using a theoretical lens, I have built a conceptual framework, using EST's five environmental contexts to contain factors operating in concert, distal and proximal to the chronically young person, over the developmental stages of infancy, childhood, and adolescence, to produce a psychosocial outcome in young adulthood.

The Chronosystem

The chronosystem is the highest level of the framework and the most distal to the young person but it is highly influential. The chronosystem contains factors that involve the patterning of environment overtime and socio-historical circumstances and perspectives. In my conceptual framework, I have extended this theoretical explanation of the chronosystem to include global concerns about the increasing numbers of chronically ill people and the escalating cost of chronic illness healthcare as well as changing health care systems and new models of nursing practice in response to these concerns. I have included a discussion about the global advances in medical science, which are constantly changing the cost and the configuration of illness and health outcomes for the chronically ill, in the chronosystem. The discussion includes a global political perspective on how to decide on the best health care system to manage vast numbers of people living longer, with the physical effects of treated diseases such as cancer and organ transplant and ongoing chronic illnesses such as cystic fibrosis and diabetes. The interactions of factors within the chronosystem have implications for the resources, perspectives, and decision making of the macrosystem.

The Macrosystem

The macrosystem contains the presiding culture that shapes the behavioural patterns, beliefs and all other factors about a group of people that are passed down from generation to generation. The macrosystem includes the institutional values, beliefs about how individuals should be treated, and resources available to them. In my conceptualisation of the macrosystem, I have extended this explanation of the macrosystem to include the NSW health care system, the NSW health care policy directions for chronic illness, political decision-making about the care available to the chronically ill and the role and capacity of clinical leadership activities. The perspectives and decisions made at the macrosystem level have a direct effect on the exo and meso systems of my conceptual framework.

The Exo and Meso Systems

The exo and meso systems of EST contain features that indirectly and directly relate to the individual. These systems link the macrosystem to the microsystem and are frequently discussed together despite their subtle differences in definition. The exosystem contains social settings where the individual does not have an active role but where the outcome of interactions within the environment influences developmental outcomes at the microsystem level. The exosystem contains the social environment, family members, the neighbourhood, the media, the presence and quality of social and health services for individuals (Bronfenbrenner, 1979). I have conceptualised the exo system as containing overarching nursing practice scholarship, frameworks for nursing practice within larger models of care, the hospital setting, hospital service models, the social support system of families affected by chronic illness and the personal skills of the individual with chronic illness. The exo system provides context and content for the experiences of the individual, where they have an active role, in the meso system.

The meso system connects the outcomes of interactions within the exo system to the microsystem. The meso system contains family experiences, school or work experiences and peer experiences interacting directly with the individual. I have extended this theoretical explanation of the meso system to include the experiences of young people with chronic illness and their families within the healthcare system, the links between frameworks for nursing practice and nursing practice and interdisciplinary interventions, clinical nursing leadership and clinical leadership activities. The specific content of healthcare interventions and nursing practice, that could potentially improve a young person's capacity to cope and adjust to chronic illness, interact with the young person creating particular experiences that have an outcome at the microsystem level. I have addressed the exo and meso systems together in diagram 2 as there is a great deal of overlap despite the difference in definition and it is often difficult to distinguish the two systems in terms of content and outcome. The most important aspect of the exo and meso systems is their capacity to link activities and outcomes between the macrosystem and the microsystem and vice versa.

The Microsystem

The microsystem level of EST contains the individual and the contexts within which they live. This context or system contains the individual, the family, peers, and other close significant family associations such as a parish priest or schoolteacher. In my conceptualisation of the microsystem, the theoretical description includes the internal world of the chronically ill young person, the hospital environment as a temporary home, the young person's family, the nurses caring for them and the impact of nursing practice. The specific phenomenon of my study is the interaction of nursing practice with the internal world of young people with chronic illness and the resultant psychosocial outcomes: in particular the role of the nurse and the content of nursing practice that interacts with the young person's internal world and which can potentially facilitate the development of personal skills to cope and adjust to living with chronic illness. This is not to say that the hospital environment is the single environment where a young person can learn these skills but given that these young people, and their families, spend so much time during childhood and adolescence in hospital I decided to explore how to strengthen the nursing and healthcare component of their developmental experiences.

Ecological Systems theory provides a comprehensive framework and theoretical explanation to organise a complex view of health and analysis factors that mediate outcomes. However, the theory does not provide a prudent detailed set of explanations to predict change, and to understand changes in health phenomena within each environment in order to influence developmental outcomes (Grzywacz & Fuqua, 2000). This was particularly relevant to my theoretical lens of the microsystem, that is the internal world of young people with chronic illness and the interplay with nursing practice. Ecological Systems Theory does not have a strong life-span developmental orientation (Elder, 1995; Santrock, 1998), in particular a stage-by-stage explanation of what is occurring in a young person's internal world. I decided to include Erikson's theory of psychosocial development to provide a set of explanations to understand and predict psychosocial development and factors that mediate developmental mastery. This additional theoretical explanation has provided an extended theoretical lens to analyse the impact of chronic illness on psychosocial development and the role or potential role of nursing practice.

In summary, EST, including the complementary role of Erikson's theory of psychosocial development, provides a framework for an interdependent, multidimensional, multilevel and interactions view of the etiology of individual developmental outcome (Grzywacz & Fuqua, 2000). Within my conceptual framework of both theories the etiology of the psychosocial outcomes for young people with chronic illness and the role of nursing practice within the healthcare world as a mediator of outcomes can be effectively explored.

Organisation of the thesis

This thesis contains a series of chapters to extend knowledge about the psychosocial development of, and consequences for, young people with a chronic illness during the developmental period of adolescence and the responsiveness of the healthcare system to meet their needs. Further, I explore the ways in which healthcare services, specifically nursing practice and clinical leadership activities, can contribute to policy development and practice model reform to optimise bio-psychosocial health outcomes for young people with chronic illness. There are three components to my work: firstly, an analysis of the practice problem and a comprehensive review of the literature, followed by a quantitative and qualitative research study and, finally, a theoretical analysis of the internal and external worlds of young people with chronic illness, including recommendations for nursing practice development and clinical leadership activities to optimise outcomes for this group.

The recommendations I put forward are an extension to the recommendations of the NSW Health Council Report (New South Wales Health Council, 2000) and subsequent projects emerging from this work (NSW Department of Health, 2003) that propose to improve health service delivery and quality of life for people with chronic and complex chronic illness.

Chapter 1 brings together the clinical problem that initiated the work of this thesis and the thinking behind the construction and organisation of this thesis. This chapter also situates the work of the thesis and my position in the work. Chapter 2 incorporates a background discussion about the chronic illness literature and the literature review for this thesis. Despite the enormity of the chronic illness literature I was left with questions about the specific psychosocial problems and experiences of the patient group in my practice context and the responsiveness of the healthcare system as whole to their specific needs. Therefore, I decided to undertake a quantitative and qualitative study to understand more about the psychosocial functioning and difficulties experienced by this group, and any links with treatment adherence.

Chapter 3 presents the study 'Treatment adherence of youth and young people with and without a chronic illness' (Rosina, Crisp, & Steinbeck, 2003). The study showed a statistically significant negative relationship between internalising behaviours and those who struggled more with treatment adherence, particularly for the young women in the study. The study findings suggested a link between physical and psychosocial health outcomes among young people with chronic illness. However, there remained questions about the responsiveness of the healthcare system, about what nursing practice development and clinical nursing leadership activities would be required to influence policy reform and service model development and to meet the young people's needs. Given the number of questions raised by the study findings and the unanswered questions in the chronic illness literature, I decided to include a theoretical analysis of the healthcare world and the role, or potential role, of nursing practice and clinical leadership to influence policy reform.

The enormity of the chronic illness healthcare world required a framework to organise and analyse the discussion in a series of contexts. I decided to divide the discussion into the two worlds; the internal world of young people with chronic illness and the interplay with nursing practice and the external world of the healthcare system, containing nursing practice and leadership activities. The theoretical analysis of the healthcare world uncovered many global events, political and social policies and perspectives that interrelate in ways that ultimately shape the professional lives of nurses, the framework of nursing practice, the capacity of nursing leadership to influence reform and the psychosocial outcomes for young people with chronic illness. Given the enormity of information and the complexity of the multiple systems in play I decided to utilise Urie Bronfenbrenner's Ecological Systems Theory as the organising framework and theoretical lens for the theoretical analysis component of my thesis.

Ecological Systems Theory, presented in Chapter 4, allows the healthcare world to be organised into five tiered systems - proximal and distal to the individual. Each system provides a context to discuss the factors and events that interrelate to shape a developmental outcome in the lives of young people with chronic illness, and the professional lives of nurses.

Chapter 5 begins the conceptual analysis with the chronosystem level of the framework. The chronosystem conceptualises global health concerns, universal events, and healthcare debates that drive changes within other systems closer to the young person's local healthcare world and the interface with nursing practice. This chapter draws together the most pertinent global drivers of change in chronic illness healthcare that include the escalating cost of medical science, the increasing numbers of chronically ill, the commercialisation of healthcare, the emerging ethical issues around the distribution of healthcare resources and the increasing shortage of skilled doctors and nurses. In this discussion, I critique the major reforms organising healthcare delivery and nursing practice in the international context of healthcare. The chapter emphasises an imperative for nurses to understand more about global healthcare and nursing practice reforms, to anticipate and plan the impact of global changes on the NSW healthcare system.

Global drivers of healthcare are expressed in the macrosystem or more local level of the NSW healthcare system discussed in Chapter 6. This chapter draws on the macrosystem part of the framework in an examination of policy directions in NSW in relation to chronic illness healthcare and the implications as well as opportunities for nursing leadership to both influence and participate in reforms. The globalisation of the world's affairs means that the driving political ideology and stability of one nation's economy can affect the political decision-making and healthcare arrangements and opportunities to optimise health states for people in other countries. Major economic and social reforms around the world can shape the values, beliefs, resources, threats, and opportunities available to citizens to organise their lives. In my conceptualisation of the healthcare world, the values, beliefs, resources, threats and opportunities offered to or imposed upon citizens by governments and healthcare organisations can also influence the configuration and availability of healthcare, thereby influencing the quality of care and health states for people. In NSW, nursing discourse about chronic illness healthcare reform is notably quiet. The dogma shaping healthcare services and models of chronic illness care seems to be more about the agenda of politicians seeking re-election rather than the needs of patients. There is emerging suspicion in the literature that scientific consortiums and the interests of pharmaceutical organisations in NSW are increasingly influencing healthcare reform (Little, 2000). I argue that opportunities exist within the macrosystem for nurses to influence and optimise how the health system is laid down, to gain understanding of whose interests drive healthcare reforms and what model of care ultimately becomes available to the community. I have termed these strategies of influence 'clinical leadership activities'. In Chapter 6, I make a number of recommendations and give strategies to enable clinical nurse leaders to effectively influence service model development and policy reform through participation and contribution.

Throughout my thesis I have identified nursing practice, knowledge, and leadership as both positions of agency and contextual factors that influence change, and as powerful mediators of responsive nursing practice, clinical service re-design and better patient outcomes. These factors are represented within Ecological System Theory as exo and meso systems that link the macrosystem to the microsystem. The mediating role at this level of the framework is reliant on a thorough understanding of how young people cope and adjust to living with chronic illness. It is acknowledged that there is already a wealth of information in the literature about coping and chronic illness, but what I was particularly interested in, was expanding knowledge about how young people cope and do not cope with chronic illness in order to establish a framework for nursing practice based on this knowledge, to development more responsive nursing and interdisciplinary interventions. I wanted to find interventions, or ways of going about nursing practice and the work of nursing within interdisciplinary team activities, that support young people in the development of coping skills to optimise psychosocial outcomes for this group.

In Chapter 7 I have brought together some of the seminal work around skill development in coping and applied these understandings to consider the ways in which nursing practice, and nursing practice within interdisciplinary teams, can facilitate coping skill development in day-to-day healthcare. At the very least, with a deeper understanding applied to frameworks for nursing practice of how skills in coping are developed for chronically ill young people, healthcare interventions may not impede coping skill development. I also intended that this work should bring new knowledge to both frameworks for nursing practice and policy reform and service model development.

I identify in Chapter 7 seven important components of coping and the important role of psychosocial developmental mastery. I argue that in some way these factors integrate or facilitate each other to enable the process of coping. These elements include psychosocial developmental mastery, a sense of coherence, the trait of resilience, the utility of social support, the strategy of normalising illness, and the role of hope in adversity. This work clearly identifies psychosocial developmental mastery as integral to the development of good coping skills for young people with chronic illness.

Ecological Systems Theory (EST) has proved a useful framework to conceptualise the healthcare world of young people with chronic illness and the specific contextual factors that can potentially mediate change to optimise outcomes for young people with chronic illness. However, the theory provides little detail about the psychosocial development of individuals, particularly across the life span, to facilitate understanding of the impact of chronic illness at different psychosocial developmental or life stages. The nursing care of these young people can sometimes be at odds with the developmental tasks of adolescence and can result in compromising coping efforts and adaptation to chronic illness. Understanding psychosocial development is critical for nurses to be able to develop responsive practice development and to inform policy reform.

Chapter 8 presents the microsystem level of EST represented by the internal world of young people with chronic illness and the interplay with nursing practice. The microsystem of EST provided a theoretical lens to analyse the internal world of young people and the interplay with nursing practice but it did not provide enough detail about adolescent psychosocial development overtime and what specific tasks were important for developmental progression. This area of analysis is particularly important to inform nursing and interdisciplinary intervention to optimise psychosocial developmental outcomes for this group. I decided to complement EST with Erikson's theory of psychosocial development. The purpose of this second framework was to analyse the impact of chronic illness and nursing practice on the psychosocial development of young people with chronic illness and to make recommendations for responsive nursing practice reform and the contribution of nursing practice within interdisciplinary interventions.

Erikson's main contribution to the understanding of human development was to bridge the gap between the theories of psychoanalysis by linking psychosocial development with the individual's social environment (Erikson, 1968; Marcia, 1987). He strongly believed that the concept of social environment plays a major role in the development of the personality. More specifically, that social environmental factors such as, the experience of peers, the school environment, cultural values, and ideals are crucial to development progression and highly influential in personality development. Erikson was particularly concerned about the developmental experience of adolescence and the interaction of a person's inner world and the social world that surrounds the person in psychosocial and personality development (Erikson, 1968). These important foundations of Erikson's theory have had clear relevance and application to my objective of expanding nursing scholarship and frameworks for responsive nursing practice to the developmental needs of young people with chronic illness.

Erik Erikson's theory is a sequence of age related stages with specific tasks and challenges to be achieved or resolved in order to progress to the next stage. The relative mastery of each stage from infancy is required to master the tasks of adolescence and young adulthood. Given the importance of incremental developmental mastery at each stage from infancy through to adolescence with a cumulative developmental outcome for adulthood, this discussion begins at infancy and continues through to the stage of young adulthood. The chapter uses case studies from my clinical practice to further illustrate the impact of nursing practice on the psychosocial development of young people with chronic illness and to make recommendations for practice development. Nursing practice and clinical leadership activities are identified throughout my thesis as important mediators of responsive practice, service model design and policy reform. The leadership discussion, that is what sorts of leadership and clinical leadership activities, at what levels of the healthcare world, required a much more detailed analysis. Therefore, I decided to include a chapter in my thesis to provide this more thorough analysis.

Chapter 9 presents potentially achievable leadership strategies and clinical leadership activities that can influence responsive policy reform at each level of the healthcare world. I emphasise that the discussion and the strategies presented in this chapter are from the perspective and scope of experience of a clinical nurse working towards skills to participate in and influence the policy development world of healthcare. The intention of this chapter is not to present a broader discussion about nursing leadership or the power issues in the healthcare world or a comprehensive discussion of all barriers to nursing leadership activities.

Their facets are acknowledged but, more specifically, I discuss and make recommendations about what the clinical nurse can achieve by bringing practice knowledge to policy reform.

Chapter 10, the final chapter of my thesis, draws together the major findings and recommendations for clinical nurses from the theoretical analysis component of my thesis. These recommendations will set down a framework of leadership strategies and activities from the clinical nurses' perspective and sphere of influence as a way forward to influence healthcare service model development, nursing practice and policy reform in ways that can optimise the psychosocial health outcomes for young people with chronic illness. Throughout my work, I argue that nursing practice, and the role of nursing practice within interdisciplinary interventions, nursing leadership and clinical leadership activities are key to development of a responsive healthcare world for young people with chronic illness. The next chapter will present a review of the literature related to the clinical context of young people with chronic illness within the healthcare world and the ways in which they cope and adjust to the impact of chronic illness during the development period of adolescence.

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Chapter 2

Literature Review: Situating the work of the thesis in the literature

Background to the Literature Review

Linking the theoretical lens and the empirical findings to the selection of literature

Literature in the area of chronic illness is extensive, with literally hundreds of thousands of papers exploring numerous aspects of the experience of chronic illness in adult, adolescent, and child populations. There is only a small amount of literature about the psychosocial health of young people with chronic illness cared for in an adult hospital and some articles that try to understand how this group cope and adapt to chronic illness. However there are no articles about frameworks for responsive adolescent psychosocial nursing practice in an adult hospital or related clinical leadership to bring about change – specifically at different levels of the healthcare world. The Ecological Systems theory (EST) helped to identify that which was most important to my objectives. I decided to take the approach of being clear about the specific phenomena I was studying, what research questions I was asking, and what a clinical nurse could do, or might be able to do, to influence models of care, frameworks for nursing practice and policy development and reform.

The phenomenon under discussion, and the research context, within this thesis is the psychosocial outcome of young people with chronic illness in an adult hospital. I wanted to understand more about the responsiveness of nursing leadership, scholarship, and practice, at each level of the healthcare world, to optimise outcomes for this group. The research question that has framed my research is: why or what factors cause some young people to cope and adapt better to chronic illness, resulting in better psychosocial outcomes - whilst other young people with chronic illness, with seemingly similar environments, achieve poorer psychosocial outcomes? Further, how do nurses identify those young people who are struggling with both their illness and the impact of treatment on their adolescent psychosocial development? I also wanted to know what nursing leadership, scholarship, and practice development, within the healthcare world, could do to improve health outcomes for this group.

The overall aim of my work has been to extend the existing knowledge in the chronic illness literature to provide a deeper understanding of the psychosocial development of young people with chronic illness and the developmental experiences of this group in an adult hospital. Further to this aim, I sought to identify specific clinical leadership activities that can influence the environment in ways to achieve responsive practice development and policy reform to the specific needs of young people with chronic illness. The healthcare world of young people with chronic illness and the professional lives of nurses are vast and complex so I decided to use an organising framework.

The framework organised the healthcare world into a conceptual model with five interconnected environments or levels. The chronosystem represents the global healthcare world of the chronically ill linked to the macrosystem. The macrosystem represents the NSW healthcare system, specifically service models, policy development, and opportunities for reform. The next levels of the framework are the exo and meso systems. These systems are the interlinking systems that connect the macrosystem to the microsystem. The exo and meso systems represent nursing scholarship and clinical leadership activities within the adult hospital. The interactions within the exo and meso systems have the opportunity to influence service modelling and policy reform in the macrosystem and the microsystem thereby, I argue, can optimise outcomes for young people with chronic illness. The microsystem level of the framework represents the internal world of the chronically ill young people and its interaction with nursing practice, and the efficacy of nursing practice within interdisciplinary teams. This framework allowed an analysis and discussion of each setting leading to recommendations about the ways in which events and activities within them can be potentially influenced to optimise outcomes for the young people.

Given the wealth of literature in relation to these diverse areas I have laid out the EST framework for each chapter and the reasoning about how using a theoretical lens for each chapter guided the selection of literature for discussion. Despite the wealth of literature about chronic illness there are comparatively few areas of research and associated practice development concerned with the psychosocial developmental needs of, and the application of psychosocial interventions, by nurses and interdisciplinary teams, for chronically ill young people in an adult hospital. Therefore, I have selected literature, utilising a theoretical lens, that would enable me to establish new thinking, argue and critique particular positions and make recommendations for practice development, clinical leadership activities, service modelling and policy reform to optimise outcomes for this group.

My specific area of study, as outlined above, has been the psychosocial functioning, stage related psychosocial development, and psychosocial outcomes of young people with chronic illness in adult hospitals and the associated frameworks for responsive nursing scholarship, practice and clinical leadership activities. In contrast to the broad literature on chronic illness, this specific area of concern offers very little information, with no definitively focused research papers. The closest area of research were the many studies highlighting the relationship between poorer psychosocial health and a greater risk for adult psychopathology amongst young people with chronic illness (Combs-Orme et al., 2002; Diseth, Emblem, & Schulz, 1999; Hansen et al., 2001; Smemesh et al., 2000; Stuber, 1996; Stuber et al., 1997; Townley, 2002). As my theoretical lens moved from trends in the global healthcare world to the NSW healthcare system I selected literature related to these discussions. At the global level, I selected literature that explained the major directions in health policy and service model development in response to increasing numbers of chronically ill people and the escalating cost of healthcare provision. These global concerns and innovations in health service delivery, including nursing practice development, had a strong mediating effect on how the NSW healthcare system is laid down and directions in chronic illness related policy reform. I therefore selected literature in relation to policy reforms and service development to organise and rationalise care for the chronically ill in NSW. I included literature that discussed both the implications and opportunities for nursing clinical leadership activities and nursing practice development.

Through my theoretical lens of nursing scholarship and clinical leadership activities as important influences in optimising health outcomes for chronically ill young people, I selected literature to understand how young people cope and adjust to chronic illness. I selected literature from a range of disciplines and applied these understandings to young people with chronic illness and nursing and interdisciplinary interventions, in the adult context of care. Finally, building on the understandings of how important psychosocial development is to the development of coping skills, and my theoretical lens on nursing practice and the internal world of young people with chronic illness, I decided to expand knowledge about the impact of nursing practice on the psychosocial development of this group. This work required literature explaining psychosocial development and related literature to support a discussion about how nursing practice, using nursing scholarship, can enhance and, at the very least, not impede the psychosocial development of this group which is so important to the development of coping skills in order to adapt to living with chronic illness.

Advances in Medical Science Increasing Survival

Chronic illness has become a major primary health problem affecting many people and families worldwide. Consequently, health services around the world are experiencing an increased demand for chronic illness healthcare over a longer, and in some cases, a normal life span. With the burgeoning cost of chronic illness care, economic, ethical, and moral questions have emerged. Such questions may include how society will keep pace with the costs of advancing medical science and how will society ensure equity in the benefits of medical science across multiple chronic diseases and configurations of bio-psychosocial impairment.

Advances in medical science have altered the implications of a child receiving a diagnosis of a chronic physical disease. Diseases such as cancer, cystic fibrosis, neurological disorders, diabetes, and major organ failure previously meant survival to adolescence was unlikely, but now adult life is increasingly a realistic outcome. For many diseases, such as cystic fibrosis and diabetes, complete cure at this time is not possible but maximum symptom management extends the course of the illness, making long-term survival with a chronic illness much more likely (Price, 1996). For diseases such as many types of cancers, cure is possible, but surviving the physical effects of treatment, its impact on psychosocial development and the implications of an unprepared health system, challenge the quality of the survival.

Given that children live longer with illness and survival into adulthood is now likely, we need to rethink what it means to achieve quality of life. The more holistic notion of a bio-psychosocial health outcome, despite having a chronic illness, may be more a realistic goal for young people. This means that treatments for the chronically ill should work toward an optimal level of bio-psychosocial functioning and a meaningful contribution to the society rather than, or whilst waiting for, a complete cure from disease. New appreciations and expectations of illness and wellness for patients will force governments, the society, consumers, health authorities, and clinicians to rethink their endeavours. The attitudes toward the chronically ill, the implications of limited healthcare research, the traditional design of health services and clinical interventions are challenging the efficacy of current health policy and reform (NSW Health Council, 2000). Healthcare service and policy reform will need to consider many different configurations of disease and disability over, in many cases, a normal life span with models of care that can address both medical and psychosocial needs.

Increasing Numbers of Chronically Ill Young People

Definitive statistics measuring the incidence of chronic illness, particularly amongst the young, are difficult to find. The following statistics provide some indication of the burden of disability and illness for children, adolescents, and families in the Australian context. An Australian Survey of Disability indicated that six per cent of Australian children and adolescents have disabilities that restrict their ability to perform daily functions (Australian Bureau of Statistics, 1993). A more recent Australian Bureau of Statistics survey reported 319, 900 of Australia's 4 million children, aged 0-14 years, had some form of disability, with more profound disability reported among 221,700 of these children (Australian Bureau of Statistics, 2004). However, the definitions of disability are very broad and somewhat ill defined despite the intention to record the number of children with disabilities of undefined origin. The definitions for the research record any restriction of mobility or any degree of limitation to perform tasks such as self-care, communication, and schooling. The nature and impact of disability as a result of chronic illnesses that afflict children today, particularly in the context of rapidly advances medical and surgical interventions, may not be adequately described or recorded with these measures of disability.

The numbers of young people with chronic illness are increasing with global figures suggesting that as many as 10-20% of children and adolescents have a chronic illness (Gjaerum & Heyerdahl, 1998). There are growing concerns about the prevalence, cost, and ongoing care for people with chronic illness in Australia (New South Wales Health Council, 2000). Escalating costs in chronic-illness care have been a major factor forcing health services worldwide to re-examine the needs of these patients and the design of not only interventions but also healthcare organisations (Hoffman, Rice, & Sung, 1996; Kyngas, Kroll, & Duffy, 2000; Little, 1998).

The level of technological care now makes it possible for many people to remain at home and have their illness treatment needs managed and monitored with fewer and shorter hospital admissions. This situation creates further challenges for the traditional organisational and financial boundaries of health authorities at organizational, budgetary, policy and practice levels. The historical boundaries between hospital and primary care have resulted in a lack of cooperation and high cost for all types of illness care (Temmink, Francke, Hutten, & Jouke, 2000). Given many young people are now able to remain out of hospital and have many treatments at home, the focus has to shift to innovative health models of care and responsive nursing practice development with a focus on bio-psychosocial health outcomes.

Longer life spans for young people with chronic disease are dependent on an increasing need for therapy, equipment, and medication. Young people surviving the threat of disease now have an expectation of a much higher quality of life (Fulton et al., 2001). This has meant there will be a growing group of young people surviving into adolescence entering adult healthcare systems facing the psychosocial challenges, and for some the distress, of adult life with a chronic illness. Put quite simply, the number of people affected by chronic illness will continue to increase with the progress of medical science. This situation will lead to an ever increasing and ageing group of survivors with more chronic, long-term and psychosocial needs in a health system that was not designed for long-term holistic care, particularly outside the hospital (Galloro, 2003).

A Seemingly Unprepared Adult Health Care System

Adult hospitals now have many young people across various wards, outpatient clinics and homecare services, where staff are often unprepared to meet their diverse needs. Psychosocial healthcare for young people with chronic illness will need to consider the tasks of adolescence such as peer relationships, at risk behaviours, developing an independent life style, optimising employment opportunities, exploring sexuality and relationships and, for some, reproduction. The task for clinicians is to understand, identify, and assist young people who may not be coping with their illness or the impact of treatment. There is increasing recognition in the literature that mental health and psychological wellbeing contribute to better treatment adherence and quality of life among young people with chronic illness (Abbott, 1998; Deatrick, 1990; Kelly & Hewson, 2000; Livneh et al., 2004; Perkins, 2002; Rudin, Martinson, & Gillis, 1988; Smith, Wallston, & Smith, 1995; Sobel, 1995). However, the literature is very diverse, making definitive conclusions to solutions less certain. In addition, the literature does not identify a way forward or with any rigour mark out drivers of better bio-psychosocial health outcomes. Contemporary thinking acknowledges that it is no longer considered sufficient to provide medical care and technologically sophisticated interventions without appropriate attention to the psychological and social impact on the young person of the illness and its treatment (Brooks, 2003; Livneh et al., 2004; Snethen, Broome, Kelber, & Warady, 2004; Suris, Resnick, Cassuto, & Blum, 1996; Yarcheski, Mahon, & Yarcheski, 1997).

Currently, knowledge about the psychosocial health of young people with various chronic illnesses as a homogeneous group accessing adult health services at various stages of the illness experience is limited, particularly in Australia. The illness trajectory follows an illness course: from the emergence of symptoms, investigations toward a diagnosis, treatments, the point of 'cure', remission from disease, the best possible symptom management and survivorship from cancer, palliative care and death. A systematic understanding of the psychosocial health of this group and their families along the trajectory of chronic illness is critical. My work facilitates the development of evidence about the role of nursing leadership in policy reform, and the development of research into the efficacy and timing of specific interventions to optimise psychosocial health outcome for these young people.

Defining Chronic Illness

There is little agreement evident within the literature about the terms and definitions around disease and illness. In terms of nursing theorising and interventions, it is important to differentiate between acute and chronic illness, and between chronic disease and chronic illness. There is contention in the literature as to whether disease, illness, and sickness by definition are conceptually the same or different entities. Susser believes that disease is an objective physiological or mental disorder, whereas illness is a subjective state, a psychological awareness of dysfunction confined to the individual (Susser, 1990). Sickness, by contrast is a state of social dysfunction, due to a disease and the associated subjective illness experience (Susser, 1990). Early classic research thinking considered that societal attitudes and expectations of a person with a particular disease contributed to the person's subjective experience of illness, developing a sick role for a person to live within (Sigerist, 1951).

Another term used in the literature to describe a state of harmony between an individual, the disease and the illness is the notion of health-in-illness. Lindsey describes health-in-illness as a synthesised view of health that is not negated by the presence of disease, but incorporates it into a perception of current health and wellness (Lindsey, 1996). An example of the harmonious presence of illness can be a young person with well-controlled diabetes or a young person with cystic fibrosis experiencing optimal symptom management and expressing a satisfying adolescent lifestyle. The concept of health-in-illness is beginning to gain recognition in nursing as an appropriate way to understand and work towards adaptation and quality of life for people with chronic illness and towards more meaningful health outcomes (Albrecht & Devlieger, 1999; McWilliams, Stewart, Brown, Desai, & Coderre, 1996).

Illness can be further differentiated into acute and chronic, particularly for research purposes. Essentially, chronic illness differs from acute illness in that it has a longer duration and generally does not end in full and permanent recovery. Chronic illness is commonly defined in the literature as a disease or illness that lasts longer than three months in a given year or necessitates a continuous period in hospital of more than one month (Barry, 1996; Price, 1996). Chronic illness often has long-term physical effects or, for some, a persisting or recurrent disability lasting longer than one year (Rutter & Tizard, 1970). In more recent literature, 'survivorship' from cancer is now described as another psychosocial expression of surviving illness and adjusting to living with the spectre of recurring illness or the potential late effects of treatment, despite being cured (Aziz, 2002; Little, Paul, Jordens, & Sayers, 2002).

A more definitive explanation of chronic illness is an illness state with measurable functional and treatment adherence characteristics (Pless et al., 1994). These measures include: limitations on activities of daily living, dietary restrictions, daily medication, attendance at specialty clinics at least twice yearly, receiving physiotherapy, occupational or speech therapy or having more than two hospitalisations or three visits to the emergency department within six months. Chronic illness clearly has many configurations and critical points of psychosocial challenge in regard to the illness itself, the demands of treatment, survival or remission and the personal impact on the young person.

Realistic health outcomes, that equally focus on psychological wellbeing as well as optimal physiological health and functioning, are relatively new concepts gaining recognition in the literature (Lindsey, 1996; Murdaugh & Vanderboom, 1997; Stewart, 2003). For many illnesses, complete cure or permanent remission is not an option, but a more holistic notion of health-in-illness certainly seems a more realistic goal. As early as 1946, the WHO clearly stated that a state of health involved physical, mental, and social wellbeing and not simply the absence of disease (World Health Organisation, 1946). Given this definition, perhaps the presence of disease does not make a state of health impossible, but a more realistic definition for people with chronic illness and/or disabilities.

Nursing theorists have long argued that health is much more than the absence of disease. The presence of health is not totally negated by the presence of disease, but more about a holistic notion of optimal bio-psychosocial health (Arndt, 1995; Neuman, 1986; Orem, 1991; Rogers, 1989; Roy & Andrews, 1991). The central assumption of these theorists is that the perception of health, even in the context of physical illness, has multiple interrelated dimensions within the individual and the environment. The challenge for nursing is to understand the markers of good health despite illness and how to influence the healthcare environment to optimise facilitators that assist young people to achieve good bio-psychosocial health.

Links Between Treatment Adherence and Psychosocial Factors

There is some evidence of an increase in the number of research findings suggesting that there may be relationships between problematic non-adherence, psychosocial difficulties, and poorer physical outcomes (Abbott, 1998; Alvin, 1992; Deatrick, 1990; Kelly & Hewson, 2000; Kyngas, 1999; Muscari, 1998; Tebbi, 1992; Wainwright & Gould, 1997). Much of this research has discovered that the problems experienced by young people around treatment adherence often reflect predictable developmental concerns about being different from their peers and their struggles with achieving independence. These concerns are often normal and predictable issues for adolescents but are often more challenging for young people with chronic illness.

Health professionals often feel frustrated when trying to improve the perceived problematic treatment adherence of young people during adolescence. The limited available research comparing treatment adherence rates among adults and adolescents have found both to be around 50% (Kyngas, 2000; Wainwright, 1997; (Wichowski & Kubsch, 1997). Decisions compromising treatment adherence are commonly about negotiating a normal lifestyle and a need to believe in the legitimacy of treatment regimens (Butler, 1996; Kyngas et al., 2000; Wainwright & Gould, 1997). Wichowski and Kubsch (1997) compared treatment adherence rates and self-perception between adolescents and adults with diabetes attending a hospital clinic. The study showed little difference in the rates for adherence to medication between the groups but there was a statistically significant negative association between treatment adherence and self-perception for adolescents and adults ($r = -0.33$, $P = 0.04$). Adolescents and adults with a negative self-perception attempted to neglect treatment regimens as a way of feeling normal or without illness. These individuals also had poorer physical and psychosocial health (Wichowski & Kubsch, 1997). Diabetics were the focus sample for this study. However, the findings are consistent with other studies that included patients with cystic fibrosis, renal disease, ulcerative colitis, and diseases associated with organ transplantation (Abbott, 1998; Brydolf & Segesten, 1996; Bunzel & Laederach-Hoffmann, 2000; Christensen, 2000; Kyngas et al., 2000; Muscari, 1998). Hence, the developmental stage of adolescence in itself may not be such a strong factor compromising adherence, nor does it necessarily represent an unhealthy psychological state. Notwithstanding these issues, efforts of health professionals to improve adherence may require a shift in thinking toward possible underlying problems such as self-perception and self-esteem among the chronically ill.

Adolescent and adult treatment adherence problems may be more about struggles with adaptation and coping with the effects of the disease itself and its treatment (Rianthavorn, Ettenger, Malekzadeh, Marik, & Struber, 2004; Smemesh et al., 2000). Given this situation, perhaps clinicians might avoid over emphasising treatment adherence as a single mediator of superior bio-psychosocial health states. A better approach might be to think more about how young people cope with chronic illness and the capacity of the healthcare system to support coping efforts and adaptation to illness (Kelly & Hewson, 2000; Rianthavorn et al., 2004; Wysocki et al., 2003). Research efforts may be better directed at understanding and measuring the psychosocial health variables that make up coping, rather than simply comparing adherence rates and disease progression (Abbott, 1998; Gledhill, Rangel, & Garralda, 2000; Kyngas & Rissanen, 2001a). The monitoring of treatment adherence has a life of its own in the medical treatment of illness and therefore a focus on coping will not detract from this work

The Experience of Chronic Illness and Psychosocial Functioning

Another discrete area of the literature is a limited number of studies that have attempted to describe the experience of chronic illness and the impact of chronic illness on the psychological health of young people with chronic illness. Some researchers have attempted to understand the experience of chronic illness as a process of adjustment or a series of adaptations to the demands of illness treatment along an illness trajectory (Frank et al., 1998; Howe, Feinstein, Reiss, Molock, & Berger, 1993; Larkin, 1987; Patterson & Blum, 1996; Price, 1996). The illness trajectory begins at the onset of symptoms or at diagnosis and follows the course of the disease. For others with relapsing type illnesses such as cancer and some immune disorders, the trajectory may halt and recommence with exacerbations and remissions of illness. This illness trajectory may continue for some over a normal lifespan or the natural progression of the disease with an early death. Price further describes the process of adaptation or adjustment as reflecting increments of emotional development and enhanced coping abilities as the disease progresses (Price, 1996). A maladaptive illness trajectory by contrast is evidence of vulnerability or emerging psychopathology (Price, 1996). If we are to consider the appropriate use of interventions for young people with chronic illness, we need to understand more about the predictors, facilitators, inhibitors, and measures of psychosocial health and adaptation to illness.

Mental, psychological, and psychosocial health are, terms often used interchangeably in chronic illness literature, depending on the instruments and the outcome measures used by the researchers. Mental health is considered a relative state of mind in which an individual is able to cope and adjust to the stressors of daily life and mental health problems occur when this balance is temporarily disturbed (Lazarus, 1991). Barry (Barry, 1996) believes mental health status, which he calls the degree of balance, is an evaluation of the functioning of the individual's intrapsychic system. Psychosocial evaluation, by contrast, measures functioning of an individual's mental status and social functioning, and the interaction between the two (Barry, 1996). Psychosocial outcome, in terms of surviving paediatric chronic illness, refers to a combination of psychiatric and social outcomes in adolescence and young adulthood (Gledhill et al., 2000). Psychosocial problems indicate psychological impairment or psychopathology, represented by abnormalities of emotions, behaviour, and relationships. We need to understand more about the emotional and social functioning of young people with chronic illness, particularly as young people enter the adult healthcare system.

Chronic illness with a paediatric onset adds a dimension of increased risk to the physical, psychological, and social developmental process of adolescence (Gledhill et al., 2000; Goldston et al., 1997; Livneh et al., 2004; Patterson & Blum, 1996; Stuber, 1996). There is growing concern that adolescents with chronic illness are at particular risk for emotional and behavioural problems and/or, in the long-term, adult psychopathology (Snethen et al., 2004; Stuber, 1996; Weiland, Pless, & Roghmann, 1992; Wolman, Resnick, Harris, & Blum, 1994). Further research indicates an association between depression and suicidal behaviour among young people with chronic illness (Burke & Elliott, 1999; De Leo et al., 1999; Druss & Pincus, 2000; Ortega, Huetas, Canino, Ramirez, & Rubio-Stipec, 2002).

The Mental Health of Young People with Chronic Illness

Many studies have explored or measured the mental health of children and young people with chronic illness. The available research findings vary in their methodology. As a result, the evidence of psychopathology among chronically ill children and young people is uncertain (Vessey, 1999). A review of the medical records of children accessing a paediatric hospital for chronic physical conditions found high prevalence of co-morbid psychological problems (Vessey, 1999). A large Canadian study of 17 626 patients examined the impact of long-term chronic conditions on mental health and the use of health services across all age groups (Patten, 1999). The findings suggested a co-existence of depression and chronic disease, but the researchers questioned whether depression and/or depressive episodes increased with the severity of the illness or vice versa. Despite the large sample size the evidence for compromised mental health for young people in this study is inconclusive, as it did not specify the numbers in each age group, disease types or illness severity of the subjects.

A large retrospective study explored whether having chronic illness since childhood increased the risk of psychosocial impairment by interviewing 487 young people aged 20-25 years (Kokkonen, 1995). Psychosocial functioning and somatic symptoms of the research subjects were compared to controls of the same age without illness. The findings suggest chronic illness in childhood lasting into adulthood is a significant risk for depressive mental health disorders in adult life, particularly for young women (Kokkonen & Kokkonen, 1995).

A meta-analysis of 60 research studies exploring the incidence of depression among children and adolescents with chronic disease found a slightly elevated risk for depressive symptoms (Bennett, 1994). Despite the large number of studies reviewed, the evidence of a relationship between depression and chronic illness may have been weak because of methodological problems. The illnesses across the studies varied from recurrent abdominal pain to other conditions such as asthma, cystic fibrosis, and cancer, with few details about severity or level of disability. A more rigorous methodology for the meta-analysis may have provided more evidence of depression amongst the samples rather than the finding of only a slightly elevated risk of depression.

A small Australian study explored the re-admission rates of children and adolescents with chronic illness over a period of one year (Kelly & Hewson, 2000). The study found that 27 children had four or more admissions, and 18 of the 27 children had major psychological and psychosocial problems identified as the reason for re-admission (Kelly & Hewson, 2000). This is a small study of only one hospital but it does gives some indication of the need for further research to understand more about the psychosocial healthcare needs of this group, as well as the psychosocial health of the children with fewer admissions.

Suris, Parera, and Puig (1996) investigated the levels of emotional distress and suicidal ideation among adolescents with and without chronic illness. The study compared 162 adolescents with asthma, diabetes, seizures or cancer with a control group of 865 well adolescents. Both groups were drawn from high schools as part of a much larger study. The researchers were unable to find any statistically significant difference in emotional distress or suicidal ideation across the illness categories compared to controls (Suris, Parera et al., 1996). Chronic illness in general was associated with an increase in emotional problems, suicidal thinking, and depressive symptomatology among females but not males, when compared to controls. The breakdown of males to females in the experimental group, 62 males to 100 females, may have over emphasised the emotional problems for females in this study. The inclusion criteria may have influenced the study findings. The young people with chronic illness who were able to attend school for the duration of this lengthy study may have been a relatively healthier group. Those with poorer attendance and perhaps poorer psychosocial health may not have been attending school during the study influencing the sample characteristics and findings. Despite possible sample problems, the findings support the need to understand more about the psychosocial health of chronically ill young people.

Concerns are emerging in the literature about an increasing suicide risk among medically ill people of all ages (De Leo et al., 1999; Druss & Pincus, 2000; Valente, 1993). Depression, a powerful predictor of impending self-harm, is commonly overlooked in the medical model of care (Druss & Pincus, 2000). In a European research study, 7589 people aged 17-39 were interviewed to explore the incidence of depression amongst the medically ill (De Leo et al., 1999). Information was collected using a checklist of common medical conditions and a self-report questionnaire about depression and suicidal behaviour. The study showed that conditions such as cancer and asthma were associated with a more than a fourfold increase in the likelihood of a suicide attempt (De Leo et al., 1999). The researchers attempted to identify psychosocial characteristics that might predict suicidal behaviour among 1269 people aged over 15 who had attempted suicide. The findings indicated that one in two of the subjects suffered from an acute or chronic illness or a chronic illness in relapse at the time of the suicide attempt (De Leo et al., 1999). These studies did not specify the types or severity of illness or the age distribution of the subjects, but the findings have profound implications for health services and future research.

A Subgroup of Chronically Ill Young People with Poorer Psychosocial Functioning

Conversely, there is also evidence that the majority of young people adapt well to chronic illness. However, there may be a sub-group of children and adolescents who develop a maladaptive response to illness (Gledhill, 2000; Patten, 1999; Stuber, 1996). This sub-group of young people may be those with greater illness severity and disability, which may increase their risk for psychological impairment, particularly depression (Brooks, 2003; Burke & Elliott, 1999; Guthrie, 1996; Livneh et al., 2004; Patterson & Blum, 1996; Stuber, 1996). Future research will need to explore this possible sub-group of young people who may be those more likely to access hospitals services regularly. Mental health or at least periodic psychosocial assessments performed during hospital admissions or clinic visits for chronic illness treatment could at least identify young people not coping adaptively to illness or experiencing psychosocial difficulties. These young people could be referred for further assessment by mental health clinicians providing opportunities for appropriate support. Future nursing practice must include routine psychosocial assessment with tools that have good psychometric properties for this population.

Conclusion

In spite of vast literature in the area of chronic illness, few studies measure the psychosocial functioning of young people among adult hospital patient populations, where the needs may perceivably be considerably greater. Surviving chronic illness to adolescence may mean an increased reliance on treatment and possibly higher levels of disability. The available literature in this area included young people (always few in number) among adult samples making it difficult to distinguish the specific issues and risks for young people. A review of methodologies exploring psychosocial outcomes of young people with chronic illness indicated that the evidence that young people are not severely compromised by chronic illness is present, but the methodologies were so diverse that the strength of this evidence is weak (Gledhill et al., 2000). Many studies failed to take into account the severity of illnesses, specific effects of illness treatments, and the initial prognoses (Gledhill et al., 2000). There are also wide variations across the studies in the age of subjects at diagnosis, sources of information, sample sizes, presence of control groups, and the psychosocial variables measured (Gledhill et al., 2000). The majority of studies draw subjects from schools or outpatient clinics of paediatric hospitals, which by nature of the context may be a healthier group, missing a possible sub-group of patients in other contexts, in hospital or at home but absent from school for long periods, that may exist.

Studies exclusively measuring the psychosocial health and functioning of adolescents with chronic illnesses in an adult hospital or specific responsive psychosocial interventions for this group were not found. The situation of young people with chronic illness surviving into late adolescence and early adulthood is very recent; thus, the opportunity to study psychosocial functioning as a component of health outcome is a more recent development. Research that is more rigorous is required in this area; in particular, to distinguish the variables that predict coping, with and adaptation to chronic illness and to identify those young people more likely to develop difficulties with psychosocial health. Further, more research is required to understand the impact of the adult healthcare system on the psychosocial outcomes of this group and what sorts of clinical interventions, clinical leadership activities, clinical service model re-design and policy reform could optimise outcomes for this group. .

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Chapter 3

Treatment Adherence and Young People:

An exploratory study of psychosocial wellbeing

In the previous chapter, I identified substantive literature about chronic illness, the increasing numbers of young people affected, and particularly the treatment adherence problems of young people. However, there is little information about the experience of coping with and adaptation to chronic illness among young people in the adult hospital context of care. Consequently, there is little information to guide the psychosocial and developmental specific aspects of health care for this group, particularly in adult hospitals.

This chapter is a report of the quantitative and qualitative exploratory study that was undertaken to understand the psychosocial functioning of young people with chronic illness in an adult hospital. This study arose out of my practice concerns identified in Chapter 1. The aim of the study was to establish knowledge about the psychosocial health of young people with chronic illness in an adult hospital. Further, I wanted to know what specific problems the group had with treatment adherence and, more generally, their struggles in living with chronic illness as a young person. I also explored the hypothesis that the concern for struggles with treatment adherence can mask psychosocial problems. The highly medicalised model of chronic illness care may not identify young people with psychosocial problems.

Nurses play a pivotal role in caring for hospitalised young people and are ideally placed to identify those at high risk of psychosocial distress. Data on the psychosocial functioning of young people with chronic illness can improve the timing and efficacy of nursing and interdisciplinary interventions targeting psychosocial distress and treatment adherence concerns. However, the task of identifying distressed young people in need of intervention is complex and involves holistic assessment skills. Without specific training in adolescent health and development, it is difficult for nurses to identify what is normal adolescent behaviour and what is concerning behaviour. Psychosocial distress may, for instance, present as non-adherence to treatment or followup care, non-adaptive illness behaviour, acting out, high-risk behaviours, anxiety, depression, self-harm and suicidality, or simply as being a 'difficult patient'.

Traditional approaches to care offered by hospital-based models do not facilitate the identification or management of high-risk young people during admissions for exacerbation or treatment of their chronic illness. Awareness among health professionals of difficulties experienced by some young people remains relatively low (Creedy & Crowe, 1996; Edwards, 1999; Stuber, 1996). Awareness of the vulnerability of young people and appropriate use of assessment tools have the potential to improve referral during the 'window of opportunity' afforded by hospital admissions. Before this will happen, however, clinicians will need clear evidence of the usefulness of such assessments and referrals.

The aim of this study was to understand the psychosocial health and functioning of young people with chronic illness and to assess if there was any relationship with treatment adherence. Further, I wanted to understand more about the difficulties that young people may experience with treatment and life in general as a young person with a chronic illness. This study was undertaken at a large metropolitan teaching hospital over a period of 12 months. The research questions included:

1. Is the psychosocial health of young people with chronic illness different from those without chronic illness?

2. What problems do young people with chronic illness have with treatment adherence?

3. What concerns do young people with chronic illness have with other aspects of their lives?

4. Is there a relationship between psychosocial functioning and difficulties with treatment adherence?

This study forms the basis of ongoing work aimed at providing clinicians with increasing scholarship and frameworks for responsive nursing practice development to assist young people in their efforts to achieve the highest possible quality of life despite the presence of chronic illness.

Method Section

Study Design

The study design is a cross-sectional survey of youths and young adults with chronic illness and includes a comparison group of participants with acute illness. This study was designed to measure and examine psychosocial functioning, treatment adherence, and concerns about living with a chronic illness among youths 12-18 years and young adults 18-24 years. The comparison group is used to compare the psychosocial functioning of youths and young adults with chronic illness with those without chronic illness. The acute illness group were also patients in an adult hospital during the psychosocial developmental period of adolescence and young adulthood but without the burden of chronic illness. This comparison sought to provide some information about the impact of chronic illness on psychosocial functioning and to assess if there was any relationship with treatment adherence. The inclusion of the acute illness comparison group would at least provide some measure of a control group that was accessible for the purposes of the study.

Subjects

A convenience sample was recruited from the daily census list of a large adult metropolitan teaching hospital. Eighty-five young people took part in the study: 44 subjects had a chronic illness and 41 were acutely ill. It was not possible to accurately calculate power to decide on sample size requirements, as a similar study could not be found and a larger sample not possible in the research context. Therefore, it was decided to recruit as many subjects into two different groups of young people as possible during the duration of the study. Gender and age data and the distribution of conditions affecting subjects in both the chronic and acute illness groups are summarised in Table 1.

Table 1: Demographics data for youths and young adults

	Youths - female	Youths - male	Young adults – female	Young adults - male
Acute illnesses (n)	n=5	n=9	n=15	n=12
Chronic illnesses (n)	n=3	n=7	n=20	n=14

Mean Age (yrs)				
Acute illnesses	16.2	14.4	20.2	20.7
Chronic illnesses	14.6	14.3	20.2	20.1
Acute illnesses				
Medical	3	3	11	7
Trauma	2	3		3
Surgical		3	4	2
Chronic illnesses				
Cancers	1	5	2	4
Eczema		1		
Pier Robin Syndrome	1			
Cystic Fibrosis	1	1	5	3
Chronic Asthma				1
Cholangitis			2	
Dandy Walker Syndrome			1	
Diabetes			1	
Neurological disorders			3	
Haematological Disorders			4	2
Liver Transplant			2	4

Chronic illness was defined for the purposes of this research to be an illness with a duration of greater than three months, and generally not ending in full and permanent recovery (Barry, 1996; Price, 1996). For this study, subjects with chronic illness had long-term physical effects of their illness or a persisting or recurrent disability lasting longer than one year (Rutter & Tizard, 1970).

Subjects with chronic illness were also required to have illness states requiring treatments and lifestyle changes that intruded into their everyday life. These included limitations to activities of daily living, dietary restrictions, daily medication, attendance at speciality clinics at least twice yearly, receiving ongoing therapeutic interventions, or having more than two hospitalisations or three visits to the emergency department within the previous six months (Pless et al., 1994).

The group of young people with acute illness was recruited from the general hospital population to allow for comparison, while controlling for the potential distress of hospitalisation. Young people with primarily mental illness or those seriously ill were excluded from the study.

Measures

Subjects were asked to complete the Achenbach self-report questionnaire; the Youth Self Report (YSR) for young people aged 11-18 years and the Young Adult Self Report (YASR) for young people aged 18-30 years. Thomas M. Achenbach and Associates developed the questionnaires initially at the University of Vermont. The measures have since been validated in many studies of young people with and without chronic illness (Brace, Smith, McCauley, & Sherry, 2000; Daviss et al., 1995; Harris, Canning, & Kelleher, 1996; Verhulst & Van der Ende, 1995). These tools were chosen because the domains of the Young Adult Self Report and Youth Self Report measure specific aspects of adolescent psychosocial development which are affected by the presence of chronic illness. Scores in the clinical range may help to identify young people struggling with the impact of chronic illness on adolescent psychosocial development and the development of coping skills. The young survey respondents without chronic illness were also in hospital with an acute trauma or illness but without the presence of chronic illness and its implications for psychosocial development.

The Achenbach measures have been used and widely validated in both population-based studies (Garton, Zubrick, & Silburn, 1995; Verhulst & Van der Ende, 1995; Verhulst, van der Ende, Ferdinand, & Kasius, 1997) and in clinical settings (McCann, James, Wilson, & Dunn, 1996; Stanger, MacDonald, McConaughy, & Achenbach, 1996; Weinstein & Noam, 1990).

The Achenbach instruments measure thinking, feelings, and behaviours over the last 6-month period in the young person's life. Respondents completing the YSR questionnaire obtain two profiles made up of several sub-scales. The first profile is made up of the Competence Scales – 'activities' and 'social'. The second is made up of Problem Scales - 'withdrawn', 'somatic complaints', 'anxious/depressed' (these first three make up one 'internalising score'), 'social problems' 'thought problems', 'attention problems', 'delinquent behaviour', 'aggressive behaviour' (these last two make up one 'externalising score') and 'other problems'.

Respondents completing the YASR also obtain two profiles that are similar to the YSR, but not the same. The first is made up of Adaptive Functioning Scales – 'friends', 'education', 'job', 'family', 'spouse' (these combine to form a 'mean adaptive score'). The second profile consists of Problem Scales – 'anxious/depressed', 'withdrawn' (these first two make up one 'internalising score'); 'intrusive behaviour', 'aggressive behaviour', 'delinquent behaviour' (the last three make up one 'externalising score'); and 'other problems', 'somatic complaints', 'thought problems' and 'attention problems' (these last four make up a 'total problem score').

The YSR for the younger group measures competence by combining mean scores for participation in activities, social behaviours, and academic abilities. Further, the profile combines the scales for thoughts and behaviours associated with the scales 'withdrawn', 'somatic complaints' and 'anxious/depressed' to form an 'internalising score', and delinquent behaviour and aggressive thoughts and behaviours to form an 'externalising score'. A 'total problem' score is also calculated.

The questionnaires are standardised in order to demonstrate deviance from normative data (Achenbach, 1991). The instrument compares mean scores of emotional and behavioural functioning for young people 11-18 years (YSR) and 18-30 years (YASR). Achenbach developed normative and clinical ranges using two comparative sample populations. The non-referred group were healthy young people recruited from high schools and universities who had not received mental health services or counselling in the last year. The referred or clinical population were recruited from psychiatric inpatient and outpatient facilities (Achenbach, 1991). The Achenbach measures were selected for this study as they are widely used and strongly validated in Adolescent Chronic Illness research (as above) to demonstrate differences in emotional and behavioural functioning compared to controls. The Achenbach measures were already in use within the service across a number of adolescent health research studies and, as a nurse researcher, I required the support of the psychologist and medical researcher within the service access to use the tool and interpret the results. I was well supported by the service in the use of these measures for the study.

In the present study, young people with chronic illness were asked to also complete a treatment adherence measure, 'Managing Your Health', developed, and piloted for the purposes of this study. A similar instrument to measure the items in the 'Managing Your Health' survey, which were focused on the research question for this study, could not be found. The theoretical understandings of the Health Belief Model (HBM) were used in the development of the measure (Mikhail, 1981). The HBM assumes that individuals are more likely to adhere to a treatment regime if they believe in the effectiveness of treatment and have a reasonable fear that if they do not comply there will be a significant risk to health and quality of life (Mikhail, 1981).

The HBM explored both the beliefs and difficulties young people experienced with treatment adherence and the implications of non-adherence for their health. The chronic illness group were asked to respond to the "Managing Your Health" questionnaire. The acute illness group did not have treatment adherence requirements and therefore did not participate in the study. The aim of the questionnaire was simply to get an understanding about the young people's thoughts and feelings about living with and managing their health with a chronic illness. The measure consisted of seven questions in total. Four questions used a five-point Likert scale to measure beliefs about the value of treatment and participants' perceived ability to adhere. Participants could, therefore, achieve an overall score between four and 20: a score of four reflecting more negative beliefs and poor adherence; a score of 20 reflecting more positive beliefs and good adherence. Question five, six and seven were open-ended and asked participants to identify specific difficulties associated with adhering to treatment; questions six and seven asked about other concerns related to living with a chronic illness. Content analysis, both quantitative and qualitative, was used in coding the responses. The opened questions were coded into themes and questions using a Likert scale and were analysed quantitatively using descriptive statistics. Categorising responses was a straightforward process because of their concrete nature.

Procedure

Research Setting and Ethical Issues

The research took place in a metropolitan teaching hospital. Ethics approval was obtained from the mandatory area health service and university ethics committees. It was acknowledged that chronically ill young people are a vulnerable group as research subjects. Young people considered by the Nurse Unit Manager (NUM) as too ill to participate when the research assistant visited the ward were excluded from the study as well as those with neurological disorders. On several occasions, the condition of young people previously excluded from the study, as they were as too ill to participate, improved and the individual contacted the research assistant via ward NUM with a request to participate. A psychologist was approached to be available in the instance that a young person could be upset by any of the questions on the surveys or if any of the issues laid out in the surveys disturbed them in any way. Fortunately, the psychologist was not required and none of the young people were upset by the study. Quite the opposite, in fact, as many of the young people and their parents were very enthusiastic and excited about the study.

Each of the young people agreeing to participate in the study received an information sheet as well as an information sheet for parents to provide more details about the study. The researcher and the research assistant explained all details about the study included on the information sheet and answered all questions. The young people, and/or their parents as relevant, were asked to participate in the study and were only included if consent was provided. It was further explained that if the young people or their parents did not feel comfortable doing the surveys and decided not to participate, it would not affect their health care in any way. The young people agreeing to participate completed the surveys either at the bedside during their admission or in the adolescent group room within the hospital as patients of the hospital.

Recruitment of Subjects

Potential participants were identified from the daily census list of inpatients at the hospital. Once identified, participants who were considered by the NUM as well enough to participate and those without neurological disorders were approached by the researcher or the research assistant and asked to complete the Achenbach self-report questionnaire and the treatment adherence survey. Information was given about the study and consent was obtained from the participants. Parental approval was obtained when the young person was under 16 years of age.

Young people recruited for the study did not have trouble in completing the questionnaires and interpreters were not required. The research or research assistant sat with the young people as they completed the surveys, answered questions, or read aloud the questions, assisting as required. The young people expressed no difficulties with the surveys; the researcher responded to any questions. The surveys took on average 25 minutes to complete. Only four young people refused to complete the surveys because they were more interested in ward activities at the time they were approached; others simply did not return the surveys without seeming to have any specific objections to the study (response rate = 67.46%, 85/126 distributed). A response rate of 70% in Adolescent Health Research using surveys is considered high (Weitzman, Guttmacher, Weinberg, & Kapadia, 2003). Therefore, the response rate of 67.48% can be considered a good response rate. Many parents and the young people themselves expressed strong support for the study, and some provided pages of comments to open-ended questions; several parents wrote letters expressing concerns about how their children would manage with their illness in the future. This information was not included in the study as it was not part of the methodology but it was inspirational and will be considered in terms of the practice development that will result from this work.

Results

Data were examined using descriptive statistics owing to the small numbers of subjects in each subgroup. Descriptive data for the YSR and YASR instruments are provided in Tables 2 and 3. Two major forms of comparisons were undertaken –

1. Comparisons between the groups with chronic illness and their counterparts with acute illnesses

2. Comparisons between the groups with chronic illness and Achenbach's clinical population.

Correlational analyses were performed to test for potential relationships between the tendency to internalise and treatment adherence; such relationships are suggested by previous research, theory, and clinical data suggestive of problems with psychosocial functioning (Daviss et al., 1995; Harris et al., 1996).

Psychosocial functioning

There was an overall trend for youths and young adults with chronic illness to obtain scores closer to the relevant clinical population, in other words, scores that reflect a clinical level of emotional and behavioural disturbance. Whereas the youths with acute illness scored closer to Achenbach's normative population, that is, more normal levels of emotional and behavioural disturbance.

Achenbach scores for Total Competence (YSR – Table 2) and Adaptive Functioning (YASR – Table 3) are measures of developmentally appropriate academic and social functioning. Meaningful comparisons of these data are particularly difficult owing to the very small group numbers in the younger groups. That being said, the groups with chronic illness consistently scored less than their counterparts with acute illnesses.

Scores for anxiety/depression, withdrawal, and somatic complaints showed similar trends, leading the participants with chronic illness to exhibit higher internalising scores (although somatic complaints are not included in the internalising score for YASR groups). Externalising scores, made up of delinquent and aggressive behaviour in the youth groups and intrusive, aggressive and delinquent behaviour in young adults, showed a similar, but less extreme, pattern.

Table 2: Mean scores by gender on the YSR scales

Scale	Acute - Female n = 5	Chronic - Female n = 3	Acute - Male n = 9	Chronic - Male n = 7
Total Competence	16.9 (2.3) **14.7 (3.0)**	11.8 (1.5) **12.6 (3.3)**	16.2 (3.8) **14.4 (2.7)**	14.4 (2.3) **12.6 (3.3)**
Anxious/ Depressed	2.8 (4.3) **6.5 (5.1)**	9.7 (5.1) **11.4 (7.2)**	4.7 (2.9) **5.2 (4.3)**	8.6 (2.1) **8.2 (6.1)**
Withdrawn	1.2 (1.8) **4.0 (2.4)**	4.3 (2.3) **5.9 (2.7)**	3.4 (2.3) **3.4 (2.3)**	5.4 (1.5) **4.8 (2.7)**
Somatic Complaints	1.2 (2.2) **3.0 (2.9)**	5.3 (3.8) **5.0 (3.7)**	2.8 (3.1) **2.2 (2.3)**	4.7 (3.45) **3.6 (3.4)**
Internalising	5.2 (8.3) **13.1 (8.6)**	19.3 (8.4) **21.5 (11.1)**	9.9 (5.1) **10.5 (7.1)**	18.8 (3.8) **16.1 (9.9)**
Externalising	8.8 (10.2) **10.5 (6.4)**	14.0 (3.5) **17.7 (9.5)**	12.0 (8.4) **11.5 (7.1)**	14.2 (7.6) **17.3 (9.6)**

Mean scores (sd) for each group – standardised means (sd) in bold

Table 3: Mean scores by gender on the YASR scales

Scale	Acute - Female n = 15	Chronic - Female n = 20	Acute - Male n = 12	Chronic - Male n = 14
Adaptive Functioning	46.6 (5.25) **48.5 (4.5)**	45.7 (4.05) **45.9 (5.0)**	49.1 (4.6) **48.1 (4.5)**	48.35 (2.9) **43.9 (6.6)**
Anxious/ Depressed	9.5 (5.0) **9.9 (6.4)**	13.6 (3.6) **14.2 (7.8)**	7.75 (6.7) **7.5 (5.9)**	11.1 (3.25) **11.5 (7.4)**
Withdrawn	2.7 (1.9) **2.7 (2.3)**	6.5 (14.2) **3.8 (2.7)**	2.3 (2.24) **2.6 (2.2)**	2.5 (1.9) **3.8 (2.7)**
Internalising	11.45 (6.7) **12.6 (8.1)**	17.05 (4.7) **18.0 (9.8)**	10.1 (8.4) **10.2 (7.5)**	13.5 (4.2) **15.4 (9.3)**
Externalising	8.7 (5.1) **7.8 (5.8)**	8.1 (5.35) **11.5 (7.9)**	9.33 (7.1) **9.2 (6.7)**	9.0 (7.4) **15.2 (9.4)**

Mean scores (sd) for each group – standardised means (sd) in bold

Treatment Adherence

Mean scores for treatment adherence showed little differences between the younger and older groups with chronic illnesses (Table 4). There was, however, a potentially important interaction between age group and gender. Young adult men with chronic illnesses rated their adherence higher than did young adult women.

Table 4: Mean Total Scores for Treatment Adherence

Group	Adherence Score
Youths	12.0 (4.4) #
Female	12.0 (4.85)
Male	12.1 (4.45)
Young Adults	14.8 (3.6) *
Female	13.7 (3.8)
Male	16.4 (2.5)

* Pearson's correlation significant (r= -.394, df 33, p =. 02)

R squared = 15.5%

Not significant at .05 (r=-.542, df 11, p=. 07)

When Pearson's co-relational analysis was carried out to test the potential relationship between internalising scores and treatment adherence, a statistically significant negative relationship was found for the young adult group. A similarly negative, but not statistically significant, correlation was found in the youth group (See Table 4 for details).

Difficulties with Treatment Adherence and Concerns About Living with Chronic Illness

A simple content analysis, using both qualitative and quantitative techniques, was conducted to bring together into categories the responses, (24 respondents in the young adult group and 6 respondents from the youth group) to the survey 'Managing your Health'. The categories revealed a number of difficulties and concerns for young people with chronic illness (see Tables 5 and 6). The majority of difficulties concerned the demands of treatment adherence taking control of their lives, the emotional and financial costs and aversions to taking medication. Aversions varied from simply hating the medication to pain, medication side effects or simply no confidence in therapeutic value. The cost of medications was an important issue particularly for the young adults; it is likely many had some responsibility or were becoming more aware of the cost involved. Another big area of concern for these young people was the control treatment adherence had over their lives. The control factor created restrictions for work, leisure and simply being forced to remember times for therapy or medication administration. Some young people had individual concerns related to the care of their children during hospital admissions or about the children's care if they, the parent, should die.

Table 5: Numbers of youths and young adults with chronic illnesses identifying specific reasons for difficulties with treatment adherence

Concerns	Youths N = 6	Young adults N = 24
Control		
Too many restrictions	4	6
I don't do it, they do it (they=mother and staff)	2	
Time control when in hospital	2	
Hard when working		7
Can't remember them all the time	6	4
Takes over your life		3
Aversions		
Hate it	5	7
Side effects worse than disease		3
Information overload, they expect you to remember, can they?	2	
Too many pills	4	11
Painful	3	12
Financial		
Expensive		
Emotional		
No point, you die anyway	1	5
Others		
Who will look after my kids		2

No difficulties	2	7
Not filled in	4	10

Concerns about living with a chronic illness were predominantly around social issues and the balancing act that accompanies decisions about optimal symptom control and quality of life for young people - rather than simply survival.

Table 6: Numbers of youths and young adults expressing specific concerns about living with a chronic illness

Concerns	**Youths** N=6	**Young adults** N =24
Having children	2	11
Passing on illness to children	1	7
Being able to have a sexual relationship	2	9
Getting married	3	5
Future employment	2	14
Not having too much sick leave		4
Being independent of parents	3	8
Limited career choices	5	3
Education, passing exams	4	7
Flexible courses	2	1
No friends or close relationships		4
Bad temper	2	
Money to survive	3	3
Appearance and body shape	2	5
What happens when my parents are too old or sick	1	3
Constant fear of infection	1	2
When will I be normal & not live on a pension	1	1
Giving up or just quit (self harm with medication or not taking it)	4	11
People don't understand	3	1
Worried about parents after I die	1	
No concerns	2	7

Not filled in	3	9

Discussion

The results of this study suggest differences between the emotional and behavioural functioning of young adults with and without chronic illnesses and, to a lesser extent, youths in the study. Although the relatively small number of subjects in some of the sub-groups make generalisation of the findings difficult, the mean scores for the chronic illness group closely resemble Achenbach's data for clinical population scores. In addition, the higher scores for internalising behaviours for the chronic illness group, particularly for females, and their resemblance to Achenbach's clinical population, highlight the struggles of some young people with chronic illness.

The scores for youth and young adults for competence and functioning suggest that frequent and at times long absences from school, related to chronic illness and required treatments, may have longterm effects on learning, psychosocial development and later career opportunities. The findings in relation to competence (YSR) and adaptive functioning (YASR) suggest that absence from educational and social opportunities may be cumulative in effect on psychosocial adjustment compromising adult psychosocial functioning. Early identification and appropriately timed psychosocial interventions may, therefore, be crucial to minimise ongoing problems and optimise psychosocial outcomes in the chronically ill.

The relationships between chronic illness and psychosocial functioning found in this study, however, will need to be validated in future studies because of the limitations with instruments. For example, Achenbach's internalising behaviour scores are a combination of scores for three subscales; anxious/depressed, withdrawn and somatic complaints for the younger group (YSR) and anxious/depressed and withdrawn behaviours for the older group (YASR). Instruments that include somatic items are believed to overestimate the severity of depression (Gjaerum & Heyerdahl, 1998; Heiligenstein & Jacobsen, 1988). When respondents actually have chronic illnesses – with accompanying physical sequelae – the potential for inflated scores increases. It is not surprising, then, that scores for somatic complaints are notably higher for the chronic illness groups in this study compared to Achenbach's clinical populations. However, it is important to note that the anxious/depressed and, to a lesser extent, the withdrawn subscale components of the internalising scores were elevated in the chronic illness groups.

Instruments that combine anxiety and depression to measure internalising behaviours also attract criticism (Gjaerum & Heyerdahl, 1998). Anxiety may be acute and appropriate where depression may be longstanding and compromising to mental health and developmental opportunities for people with chronic illness (Lovibond & Lovibond, 1995). Despite Achenbach's 6-month retrospective framework for the self-rating of feelings of anxiety and depression, it is unlikely that young people can easily distinguish between the two; the potential for over or underestimation increases. This approach to screening for depression and anxiety has, therefore, the potential to compromise the efficacy of psychosocial interventions.

The association between high internalising behaviours and poorer treatment adherence in young adults aged 18-24 years suggests that the emotional and behaviour functioning of young people with chronic illness is an important factor to consider when trying to improve treatment adherence. This factor must be considered in relation to the myriad of other problems that lead to poorer adherence to treatment and the consequences for individuals and the society.

The cumulative negative effect of ongoing psychosocial distress associated with living with chronic illness on adolescent development and mental health outcomes are not adequately addressed within current systems of health care and should be. Screening young people for psychosocial and treatment adherence problems during hospital admissions for exacerbations and treatment of chronic illnesses may lead to appropriate referral, early intervention and improve the efficacy and timing of psychosocial interventions.

Nurses, with their frequent and ongoing contact with young people with chronic illness, are in a pivotal position to routinely assess psychosocial functioning and other problems that may impact on treatment adherence. The young people involved in the study, across the chronic illness groups expressed many problems with treatment adherence and living with chronic illness. These problems were specifically about relationships, having children, coping with illness and treatment, employment and careers, independence from parents, hopelessness, education and financial issues. These findings informed my decision that a deeper understanding was required about the psychosocial development and functioning of young people with chronic illness, and about how these young people cope and adapt to illness and the implications of treatment in their day-to-day lives, and the responsiveness of the healthcare world containing nursing practice to address their needs. Many of the difficulties and concerns expressed by the young people in this study could be identified and addressed or supported by psychosocial nursing, interdisciplinary interventions, and/or referred to other appropriate services

Conclusion

Young people with chronic illness most likely have an increased vulnerability to poorer psychosocial functioning compared to their peers without chronic illness. It was identified in this study that young people with poorer psychosocial health also had difficulties with treatment adherence; particularly in the young adult group. However, many young people in the study had multiple psychosocial concerns despite having seemingly no difficulties with treatment adherence. Utilising better treatment adherence, as an indicator of good psychosocial health, may be misleading.

Psychosocial assessment should be added to the healthcare of young people during hospital admissions, and those attending clinic visits, at various points along the trajectory of chronic illness. Appropriately sensitive screening tools used by nurses can identify young people struggling with their illness and its treatment, enabling early psychosocial intervention or early referral to other therapeutic services. Early identification and interventions for young people not coping with their illness may reduce vulnerability to mental health problems, improve treatment adherence, lead to better bio-psychosocial functioning and protective factors for psychosocial health in adult life. Treatment adherence rates may be an indicator of better psychosocial functioning but should not be the only focus of research designs and may in fact mask underlying problems coping with illness.

The current relationship between the advances in medical science and quality of life outcomes for young people with chronic illness and the subsequent systems of health care need to be challenged on social, ethical and economic grounds. Nevertheless, improvements in psychosocial health outcomes for this group not only have benefits for health services in terms of cost savings, but also on a personal level for the lives of individuals and families affected by chronic illness. The findings of this small study, despite its sampling and instrument problems, remind us of the need to raise awareness of the psychosocial needs of young people with chronic illness and their families. For some young people, their struggles with life may underpin treatment adherence problems. Future nursing research and practice development will need to go further than exploring interventions that improve adherence among young people. A deeper understanding of the process of coping with chronic illness and the responsiveness of the healthcare world is required.

These findings have provided further knowledge about the psychosocial health and functioning of young people with chronic illness in an adult hospital, the difficulties with treatment adherence, and specific concerns that a young person living with chronic illness may have. There were still many unanswered questions, particularly about the capacity of the healthcare world to both identify psychosocial needs within the medical model of care and provide responsive interventions. Treatment adherence problems are clearly the link to identify many young people struggling with the impact of illness and treatment, but not for all young people. However, as a result of this study, I came to the position that improving psychosocial health and functioning may improve treatment adherence and illness stability. I decided that these findings would require a deeper analysis, particularly of the internal world of young people with chronic illness during adolescence and the responsiveness of the healthcare world, containing nursing practice, to identify and meet their needs.

The next chapter will begin the third component of my work, the analysis of the healthcare world of young people with chronic illness and the professional lives of nurses. In this next chapter, I will present the EST framework.

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Chapter 4

Bronfenbrenner's Ecological Systems Theory

Introduction

This chapter presents Bronfenbrenner's Ecological Systems Theory framework, which I use to organise and explore the responsiveness of the healthcare world to the psychosocial needs of young people with chronic illness in the chapters that follow. A research study was presented in the previous chapter that explored the psychosocial health and the psychosocial problems experienced by young people with chronic illness in an adult hospital. The study findings suggested the presence of a subgroup of young people with chronic illness who have poorer psychosocial health when compared to their peers without chronic illness. The study findings also suggested that within the chronic illness group some young people had greater struggles with treatment adherence and more psychosocial difficulties than other young people with chronic illness. The healthcare world, particularly in the adult hospital, may be unprepared for the complex healthcare needs of young people with chronic illness, particularly during adolescence. These findings provided some evidence to support my initial practice concerns about some young people with chronic illness and the capacity of nursing practice and interdisciplinary interventions to meet their needs.

Why I Used Bronfenbrenner's Ecological Systems Theory

A young person during adolescence experiences a great deal of change. The presence of chronic illness adds another dimension of complexity and challenge to everyday life. The internal world at this time of life hosts much physical growth and psychosocial development. The interface with the external world, dominated for them by the healthcare services, is immense with multiple settings and contextual factors that impact on the psychosocial health and wellbeing of the chronically ill young person. The healthcare needs of this group frequently cut across physical and psychosocial domains creating a number of challenges for healthcare services.

The research presented in the previous chapter generated further questions for me about the seeming ambiguity of the healthcare world and the responsiveness of nursing to the diverse and significant psychosocial needs of the chronically ill. I considered at the end of my study that aspects of nursing leadership and practice were in fact central to whether or not young people coped with and adapted to living with chronic illness.

There are multiple settings and interactions that make up the healthcare world with numerous contextual factors that may influence the day-to-day lives of young people directly and indirectly. Nursing leadership and practice overarch many of these healthcare settings and interactions. The ability of nursing to influence policy directions and the responsiveness of nursing practice to the needs of young people with chronic illness was unclear to me beyond the more technical 'hands on' role in patient care.

The fact that the role of nursing and its capacity to influence change is difficult to identify beyond the patient interface makes it difficult for nurses to know how to help patients but also how to develop a more responsive healthcare environment and system. A review of the literature in Chapter 2 identified a vast, complicated and somewhat conflicting view of the psychosocial health of young people with chronic illness and the responsiveness of the healthcare world to their needs. The literature is clear that there is a risk that opportunities for healthy psychosocial development and adaptation to illness may be compromised if the healthcare world does not respond appropriately to the diverse needs of the chronically ill. Another issue within the literature is that much of the research focuses on comparing treatment adherence rates, mental health and disease states of the chronically ill. There is little attention given to environmental factors, such as the healthcare system as an entity, the responsiveness of nursing practice, and the interplay of these factors in the bio-psychosocial health outcomes of young people with chronic illness. The literature has little to offer in the way of evidence-based solutions, such as multi-level environmental interventions or nursing leadership strategies, to influence effective change for this group.

It seemed to me that the complexity and seeming fragmentation of the healthcare world has made it difficult for nurses to understand where and how to effectively participate in change and reform that optimises psychosocial health outcomes for the chronically ill. The healthcare world is vast and immensely complicated, requiring a way of making sense of the numerous settings that overlay opportunities for nurses to participate in reform and influence effective change in health outcomes. Given this situation, I decided to utilise a conceptual framework to organise and analyse the healthcare world, its interface with the chronically ill young person and the professional lives of nurses. The framework I chose is Urie Bronfenbrenner's Ecological Systems Theory (EST). This conceptual framework situates the young person within the healthcare world and enables an analysis and discussion of the healthcare environment. The framework organises the environment into five different levels or environmental settings, allowing environmental factors within each level and interactions between the levels to be analysed. The key feature of EST that has application within my conceptual framework of the healthcare world is what Bronfenbrenner calls bi-directional influences at all levels of the framework (Erikson, 1968).

Who Was Urie Bronfenbrenner and Where Did His Thinking Come From?

Urie Bronfenbrenner, a Russian born American psychologist, began his career as a musician. Following a short musical career he went on to study psychology, with his clinical work beginning in the military during World War II. Bronfenbrenner's early work was concerned with the effects of social adversities such as world wars on the psychological development of individuals (Bukowski & Cillessen, 1998). Bronfenbrenner strongly believed that human development is a result of interactions between the individual and the environment they live within. Early research by Bronfenbrenner compared the socio-cultural context of children growing up during the early twentieth century in two vastly different cultures such as Soviet Russia and America (Bronfenbrenner, 1971). The research clearly linked environmental factors to quality of psychosocial development outcomes for the children in the study. The children raised within these two diverse cultures experienced different beliefs and value systems that had profound effects on developmental outcomes. This research led Bronfenbrenner toward his now renowned ecological perspective that the environmental context where people live is as influential as inborn factors in shaping human development (Bronfenbrenner, 1971; Bukowski & Cillessen, 1998).

The argument that psychosocial development cannot be understood without considering the environment is not new. The notion has its origins in evolutionary theory where there is an appreciation that organisms evolve partly in response to factors in their environment. These factors may be distal or proximal to the organism. Within the context of human development the distal environment incorporates the historical context of an individual's life; the proximal environment encompasses the developmental context in which the individual exists (Bukowski & Cillessen, 1998). Bronfenbrenner's ecological systems theory is derived and extended from Kurt Lewin's theoretical perspective that human development is a product of an interaction between the person and their environment. Bronfenbrenner extended this perspective with the idea that the environment actually contains a number of environments with environmental factors that shape each individual's development. Each environment, with or without the individual present, has diverse contextual factors and conditions. In addition each environment outside the immediate setting can have profound effects on the developmental outcome of the individual (Bronfenbrenner, 1979).

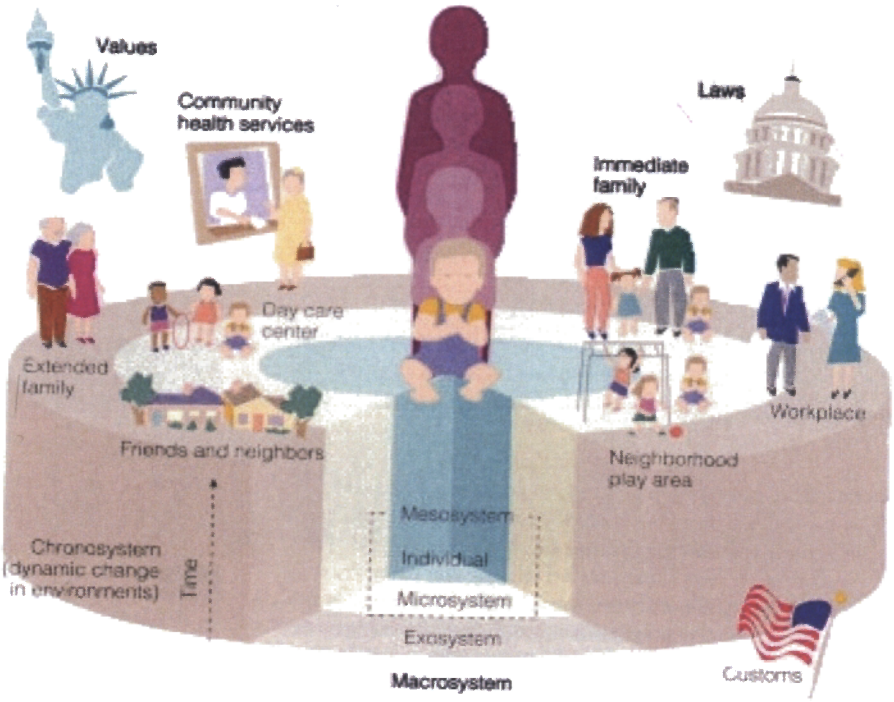
Bronfenbrenner stated in his early work that an understanding of an individual's social development is important in understanding the factors about the individual's social structure and relationships (Bronfenbrenner, 1979). In later work he added that, unless these factors are taken into account, the results can provide misleading conclusions about the drivers of change within environments or mediating contextual factors that shape human development (Bronfenbrenner, 1989). Bronfenbrenner adapted this formula by substituting behaviour in the original Lewin equation with development as the joint function of person and environment (Bronfenbrenner, 1989). Another key revision to the original Lewin theory was the appreciation of the concept of historical time-related events and resultant developmental outcome at a particular point in time (Bronfenbrenner, 1989).

Ecological Systems Theory (EST) was developed to address a perceived lack of attention to the social context of individuals within existing psychological developmental theories (Bronfenbrenner, 1979). This more contemporary view of human development put forward by Bronfenbrenner in 1979 focuses on the significance of the interaction between the person and a series of environments that they live their lives within. These environments include environmental factors or mediators that, at a particular point in historical time in the individual's life, can have a direct influence on psychological development (Bukowski & Cillessen, 1998). This perspective contends that environmental attributes at five different levels of proximity from the individual have salient affects on the developmental outcome of individuals (Bronfenbrenner, 1979). Each environment, with its environmental factors, has been used to explain human developmental outcome. This explanation extends to the potential ways of mediating environmental factors to influence human developmental outcome. Bronfenbrenner also holds that it is not only exposure to the particular environment that affects human development, but the individual's subjective response to the environment, that ultimately shapes the course and quality of development (Bronfenbrenner & Morris, 1997).

Subsequent critique of Bronfenbrenner's theory maintains that it ignores the contribution of biological and inter-personal factors in psychosocial development (Aldridge, 1997). Bronfenbrenner, following such criticism, expanded the theory to include a greater attention to the contribution of intrapsychic and interpersonal factors in psychosocial development (Bronfenbrenner, 1995). Personal attributes of the individual and others in the environment, whether biological or environmental in origin, can invite or discourage interactions. These interactions or ecological niches can facilitate or inhibit psychological and social development (Bronfenbrenner, 1989). Ecological niches 'are particular regions in the environment that are especially favourable or unfavourable to the development of individuals with particular characteristics' (Bronfenbrenner, 1992 p.194). Bronfenbrenner's theory suggests that change or modification to any level of the environment can enhance or inhibit psychosocial developmental outcomes for individuals and groups. This tenet of the theory has significance for my thesis, which is that environmental factors in the healthcare care setting such as nursing leadership, knowledge and practice development can create ecological niches within and across proximal and distal environments in the lives of young people with chronic illness. I argue in the ensuing chapters, as I explore Bronfenbrenner's EST, that nursing leadership, knowledge and practice development are factors that can, with appropriate enhancement to meet the needs of and advocate for young people with chronic illness, set in motion the appropriate reforms to policy and healthcare interventions to facilitate, or at least not impede, the psychological and social development of this group.

Understanding Ecological Systems Theory

Diagram 3



This chapter now examines and discusses each of the five environmental levels or developmental settings (see diagram 3) of EST, utilising examples and the literature to explain the use of the theory. Bronfenbrenner used the term human development in his early work to describe the psychological and social development of individuals (Bronfenbrenner, 1979). Recent researchers have used the term psychosocial development (Eicher & Erekosima, 1997; Sontag, 1996). In this thesis, I use the term psychosocial development to explain the psychological and social development of individuals.

The Chronosystem

The world is a big place, with multiple events that impact on the lives of individuals, often well out of their control. These more global events or situations affect individuals, most often indirectly from a distance. The chronosystem environment of Bronfenbrenner's EST contains the drivers of change in more local settings and environmental structures such as the community resources, individual opportunities in life and cultural beliefs. Bronfenbrenner defines the chronosystem as the dimension of time and an explanation for change over time, which he describes as the lacuna of his earlier work and that of his predecessor Karl Lewin (Bronfenbrenner, 1989). The chronosystem, a time-based dimension, refers to a patterning of more global and historical environmental events, worldwide concerns, and major transitions over the life course of individuals. Changes in the chronosystem instigate opportunities or at times disadvantages in 'resources structures' for individuals in local environments.

Historical change over time can shape values and beliefs that become the social fabric of a community. The origin of these drivers of change can be global events such as a world war, a global economic depression, in some areas generations of religious hatreds amongst community groups or the current worldwide threat of terrorism. Bronfenbrenner also refers to major life transitions as having chronosystem or global effects on individuals, such as the birth of a sibling, beginning school or within the person such as puberty or severe illness (Bronfenbrenner, 1989).

Historically, chronosystems such as the Great Depression of the 1930s or the Great Wars of the 20th century have had an enormous impact on the lives of individuals (Bronfenbrenner, 1979). Chronosystem effects may be time-limited with impacts so salient that they alter the life course of societies, cultures, and individuals. Historical events such as the holocaust in

Europe and the stolen generation of Australian aboriginals last century have had profound effects on the life course of individuals affected by these events (Gigliotti, 2003).

A conceptual study of the chronosystem affecting fatherhood across four historical time-periods in America found a distinct evolution of the role of fathers related to global events within each time period (Pleck & Pleck, 1997). I have extended this discussion to illustrate the role of chronosystems across decades and the impact on outcomes for the lives of families, and particularly children. Further, this extended discussion will demonstrate how the role of nurses has changed, and will need to continue to change as we experience each new chronosystem.

As an example of role change, the stern-natured father emerged out of the colonial era as the protector and moral role model of the family. He was uninvolved in childbirth or childcare, except for delivering fierce discipline. It was his role in society that decided who his children would marry (Pleck & Pleck, 1997). The 1830s through to the 19th century affirm the father as the breadwinner, often away from family and, when at home, disconnected from family activities. He remained uninvolved with childbirth but decided on spouses for his children. From the turn of the century until 1970s, new expectations of fathers developed. He no longer had a role in choosing his children's spouses but became a close paternal figure playing with and instructing his children. However, fathers still did not share child-rearing responsibilities (Pleck & Pleck, 1997). Since the 1970s, the father has become a highly involved figure in all aspects of marriage, childbirth, and child rearing. He now gives advice and instruction to both sons and daughters in non-gender specific language and shares custody in the case of divorce (Pleck & Pleck, 1997).

Pleck's conceptual analysis speculates about what social, cultural, historical, political, and economic contextual events seeded these dramatic effects on the role of fathers over the years. Events such as fathers going away to war, migration preceding other family members and at times travelling to distant locations to work would have influenced the changing role of fathers (Pleck & Pleck, 1997). In more recent times, factors such as the aggregation of people into cities offering local work opportunities for men, and women entering the workforce, may explain the more involved role of fathers in family life. Currently, with the almost global economic imperative forcing both parents into fulltime work, many children are spending much of their early developing years in childcare centres and the school system. This situation renders child-raising practices to the belief system of popular cultures or to those of the state, reducing the influence of parental beliefs and values on child development. The impact of this situation is yet to be fully appreciated. I have expanded on this discussion to show the impact of world events over a long period on the lives on individuals to demonstrate the role of the chronosystem. This illustration will have applied significance to the chronosystem effect on the healthcare world discussion in Chapter 5.

Other research has explored the chronosystem effect of parental divorce on the lives of children. This research measures the impact of separation from a parent at particular points of time from initial parental separation through to the divorce, and ultimately the return of relative life stability (Hetherington, Cox, & Cox, 1995). Negative psychosocial effects often peak in the first year, ending with a period of relative stability after two years, with the effects more negative for sons than for daughters (Hetherington et al., 1995).

A more recent study utilised the chronosystem concept to explore depression amongst rural black women. The researchers point out that many studies ignore the socio-historical contextual circumstances of sample populations. The social circumstances of rural black women in this study, such as oppression and exploitation, had significant effects on their day-to-day experiences and clearly contributed to the diagnoses of depression (Brown, Brody, & Stoneman, 2000). The authors argue that, ignoring the heterogeneous socio-cultural contextual experiences of women particularly when they vary across race and class, compromises a full understanding of depression and hence its treatment (A. C. Brown et al., 2000).

The Macrosystem

Significant historical events and social circumstances clearly shape the structure and constitution of the socio-cultural context where people live their lives. Bronfenbrenner describes this more local social environment as the macrosystem. The macrosystem, shaped by drivers in the chronosystem, contains community resources, hazards, life course options, and patterns of social interchange, historical cultural beliefs, and values. Interactions between elements within the macrosystem determine patterns of behaviours such as child-raising practices and societal attitudes that are passed down from generation to generation. The legal, legislative, and parliamentary systems that govern societies are an aspect or product of the interplay of agents within the macrosystem. Other elements of the macrosystem include the mass media, popular television, education curricula, health, and social policy. The macrosystem is amenable to change by driving forces from other settings (Bronfenbrenner, 1979). For example, public forums held by parents of handicapped children drove legislative changes in 1986, bringing amendments to the Education of the Handicapped Act, Commonwealth of Australia, 1986. These amendments fundamentally changed the values and beliefs held by the society about the education of handicapped children and the opportunity for community groups and families to be more influential in the mainstream school agenda (Malouf & Schiller, 1995; Sontag, 1996). This new collaborative brought together other systems – home, community and school to facilitate educational opportunities and much needed improvements in the quality of life of handicapped children (Malouf & Schiller, 1995).

Bronfenbrenner's theory holds that the belief systems and the actions of significant people in the child's world can define and re-define the goals, risks, opportunities and processes within the society that shape psychosocial developmental outcome (Bronfenbrenner, 1992). Expanding on this notion, the argument of this thesis is that the belief systems that prevail in the healthcare world and the actions of health professionals would indeed define and determine the goals, risk, opportunities and shape the healthcare world of the chronically ill. The current worldwide concern by governments about the cost of chronic illness care, the increasing numbers of chronically ill and the demands by public interest groups for more effective healthcare services have forced a rethink in the efficacy and capacity of healthcare services to contain costs and improve outcomes for the chronically ill (Leeder, 1998; New South Wales Health Council, 2000; NSW Department of Health, 2004). Economic rationalism and policy reform dilemmas have now emerged, instigated by the spiralling costs driven by worldwide advances in medical science. This situation raises the question of what will be an ethical distribution of healthcare resources and what impact this will have on the bio-psychosocial health outcomes in the more day-to-day lives of the chronically ill (Little, 1998). On the other hand, this situation or impasse provides opportunities to re-evaluate the efficacy of healthcare interventions for the chronically ill.

Exo and Meso Systems

The macrosystem is linked to more immediate face-to-face settings of individuals by the exo and meso systems. The exo system contains linkages and processes taking place between two or more settings, with at least one setting not involving the developing person, but which has consequences for the developing person (Bronfenbrenner, 1989). Examples of exo systems where a child may not be present are the context where parental friends and relatives meet, an illness support group or the workplace of a parent. These settings may improve the social support for parents of the child with chronic illness but do not ordinarily include the child. In contrast, the meso system provides a context for linkages and processes taking place between the child and two or more settings but with the child an active participant. Examples of meso systems may be a child's peer group, school friends or members of an illness-specific peer support group. Activities or the quality of activities within exo and meso systems have consequences for other settings or systems that impact on the psychosocial development of children in positive and negative ways.

The exo and meso systems are complex systems to explain but the following example will demonstrate the impact and outcome of mediation of these systems. Children exposed to community violence and the experiences of poverty are at greater risk of developing aggressive behaviours in the school setting (Eamon, 2001). On the other hand, local interventions that reduce community violence such as reducing overcrowding in neighbourhoods and enhancing community social activities can indirectly reduce aggressive behaviour of children in the school environment (Eamon, 2001). The actions of people and environmental conditioning can influence opportunities, hazards, and developmental outcomes for individuals and communities. This process can occur or be instigated at any level of the five ecological levels and influence change in a ripple effect across each of the levels in a bi-directional manner.

The Microsystem

The microsystem of Bronfenbrenner's Ecological Systems Theory is the closest environmental setting to the individual. The micro system consists of the individual, family members, significant other people, and material factors in immediate contact and face-to-face contact with the individual. A micro system consists of 'a pattern of activities, roles and interpersonal relationships experienced by the developing person in a given setting with particular physical and material features, containing other persons with distinctive characteristics of temperament, personality, and systems of belief' (Bronfenbrenner, 1989 p. 226). These experiences include relationships and interactions between family members, friends, neighbours, teachers, community elders, religious leaders, and health workers (Bronfenbrenner, 1989).

The interplay of factors and experiences within the microsystem affect how individuals accommodate schemas and beliefs about themselves and the world around them

(Bronfenbrenner, 1989; Eicher & Erekosima, 1997). For example, an adolescent may role model the physical attributes or behaviours of a famous musician, sport hero, or cult figure as they experiment with the achievement of individual identity and their position in the future world. Parental figures may place limits around this behaviour or offer alternatives to influence life choices, such as enrolment in a private school, overseas travel, or enforcement of strict religious beliefs. Ecological niches or environmental conditions can be created within the developmental environment to increase opportunities for more positive psychosocial development or to buffer the effects of more negative experiences. Interlinking factors between each system and ecological niche within the environment drive change like a 'ripple effect' through each level of the environment, in both directions in proximity to the individual.

A great deal of research has used the ecological systems' framework to organise and analyse complex social systems and the unique circumstances of individuals (Eamon, 2001; Johnson, Howard, Dryden, & McGuire, 1998; Swanson, Spencer, Dell'Angelo, Harpalani, & Spencer, 2002). Researchers using an ecological perspective argue that health problems in the last century have shifted from infectious diseases to chronic illnesses in origin (Grzywacz & Fuqua, 2000). However, despite this fact, healthcare research designs have, largely, not re-orientated to accommodate this change. The presenting problems of the chronically ill have a multitude of behavioural, social, and psychological dimensions closely integrated with environmental factors. Healthcare research now requires a greater attention to environmental phenomena as well as biological markers not only to understand and improve health outcomes, but also as an impetus for interventions.

In healthcare most clinicians intuitively believe that interventions that aim to improve lifestyle factors for physically ill people lead to more positive health related behaviours (Grzywacz & Fuqua, 2000). There is also a significant amount of research clearly identifying the role of environmental factors, such as social support and coping resources, as crucial to sustainable improvements in health outcomes for people with chronic illness and disability (Dunst, Trivette, & Cross, 2002; Patterson, Garwick, Bennett, & Blum, 1997; Pollachek, 2001; Sontag, 1996; Tak & McCubbin, 2002; Trask et al., 2003).

Ecological systems theory has been used extensively in the literature to explore the relationship between the experience of significant social adversity for individuals and communities and the protective factor of resilience (Bailey & Stegelin, 2003; Eamon, 2001;

Johnson et al., 1998). The resilience literature frequently uses EST to organise and analyse the social environment of children and adolescents facing significant adversity. This research seeks to identify factors in the environment that promote the development of the personality strength of resilience (Howard & Johnson, 2000; Rutter, 2000; Werner, 1997).

An Australian study used the EST framework to organise the environment of children living in disadvantaged areas of South Australia (Howard & Johnson, 2000). The researchers interviewed 125 randomly selected children, aged 9-12 years, and 25 teachers about what they thought was important to help children who experienced a 'tough life'. The children and teachers were also asked why they believed some children did well anyway and why some children did not do well (Howard & Johnson, 2000). All of the study subjects believed that the presence of a loving and supportive family was the most important factor deciding the psychosocial outcome of children despite being poor. Factors about school are also important, such as the capacity of teachers to help parents not 'handling' their children. A number of children stated that schoolteachers could help 'kids not doing OK because of their family' by talking to them and assisting with homework. Many of the children and the teachers felt the school should provide a safe and caring environment for children as well as allowing and encouraging parents to become involved in the school community. The perception of nurturance in the school environment of children was thought to be a highly significant factor in making a difference for 'kids to be OK'. Further, the community was perceived to have a responsibility to provide recreational facilities, to welcome shopping centres for children to 'hang out with friends', safety houses and friendly communities where adults acted in a kindly and protective way towards children. The study findings emphasised that it is not always possible to change macrosystem factors such as the child's predicament of poverty. However, changes well within the capacity of those in daily contact with the child can improve psychosocial outcomes.

The argument in the Howard and Johnson (2000) study clearly has relevance to the argument of this thesis that nursing, a constant contextual factor in the healthcare world of young people with chronic illness, can influence healthcare reform at macro and microenvironments of young people with chronic illness. The organisation of the environment in this way has also enabled the development of specifically targeted solutions, either at the micro level to increase the resources of individuals, or by advocating at higher-level environments such as government for social policy reform (Corcoran, Franklin, & Bennet, 2000; Eamon, 2001; Howard & Johnson, 2000).

Criticisms of Bronfenbrenner's Ecological Systems Theory

The Bronfenbrenner EST, presented out in this chapter, has provided a useful framework to conceptualise the complex healthcare world of young people with chronic illness. However, like all theories, subsequent critique in the literature has identified some weaknesses that require discussion. The primary tenet of Bronfenbrenner's theory emphasises the role of environmental conditions and specific environmental factors on psychosocial outcome. A major criticism of the theory is the fact that it does not have an adequate framework to conceptualise the stages of life or life course transitions (Santrock, 1998). This criticism is particularly relevant to the discussion of the experience of adolescence for young people with chronic illness. The internal world for young people with chronic illness is undergoing considerable change and is challenging emotionally and cognitively. For many young people with chronic illness, this significant developmental period is occurring at the same time as exacerbations and remissions of illness. In response to this theoretical weakness the Elder life course theory was developed (Elder, 1995). However, this theory still does not contain adequate detail about the developmental period of adolescence, but emphasises the impact of historical events such the experience of war on the psychosocial outcome for older people. In response to this identified weakness in the Bronfenbrenner's ecological systems theory, an additional framework to analyse and discuss the psychosocial development for young people with chronic illness is used in Chapter 8.

Another criticism of EST is that little attention is given to the degree of embeddedness of individuals within their environments. EST accepts that each developing person experiences and is embedded within or is influenced by each of the five nested contextual settings, but does not address the degree of variance in embeddedness by each individual or discrete community groups. Research that attempts to explain why some individuals find adaptation to a given sociocultural environment far easier than do others suggests that the degree of embeddedness of individuals within their environments varies and is an important factor in understanding or improving developmental outcome. Some individuals appear to be fully embedded within the five nested ecological environments, but more commonly, individuals are only partially embedded (Sternberg & Grigorenko, 2001). The notion that individuals may interact with agents and contextual environments in differing degrees is certainly an important critique of Bronfenbrenner's theory. However, this proposed weakness in the theory will not be examined to any depth in this thesis but it may be relevant to future research.

Given Bronfenbrenner's work discussed in this chapter and taking into account the criticisms, his EST still nevertheless has great potential to explain large and complex environments such as the healthcare system. EST has been used to analyse both small and large research contexts (Eicher & Erekosima, 1997; Howard & Johnson, 2000; Sontag, 1996). This work has provided a better appreciation of how interactions between social environments and individuals shape psychosocial outcomes.

Conclusion

EST, despite the few weaknesses already discussed, is an effective conceptual framework in which to analyse each level of the healthcare world and I use it in subsequent chapters of this thesis. This analysis is used to conceptualise a complicated healthcare world and the professional work of nurses into a meaningful framework. The argument of this thesis is that nursing leadership, scholarship and practice are the interlinking factors between the various levels of the healthcare world that can affect i.e. carry out, appropriate healthcare reform. Nursing will need to consider both human and environmental factors at multiple levels in order to understand more about the impact of the healthcare world and the effects of social and illness related adversity on the psychosocial health of the chronically ill. This understanding will assist the profession to influence interdisciplinary clinical practice development and to participate more effectively in healthcare debate and reform.

The following chapters conceptualise the healthcare world into each level of Bronfenbrenner's EST. The discussion analyses the impact of the healthcare world and nursing practice on the psychosocial wellbeing of young people with chronic illness. The following chapter begins this discussion with an examination of the chronosystem level of Ecological Systems Theory, which contains the drivers of healthcare reform. This conceptual analysis identifies the impact on and opportunity for nurses to take on a more strategic role in healthcare reform and how this process can shape not only policy and practice development but also the professional lives of nurses.

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Chapter 5

The Chronosystem Level of Ecological Systems Theory:

Introduction

The theoretical analysis is continued in this chapter, that is, an analysis of the healthcare system and the professional world of nursing as it relates to the psychosocial needs of young people with chronic illness. The analysis begins with the chronosystem, the highest level of the EST framework (see below diagram 4 in orange).

The Chronosystem

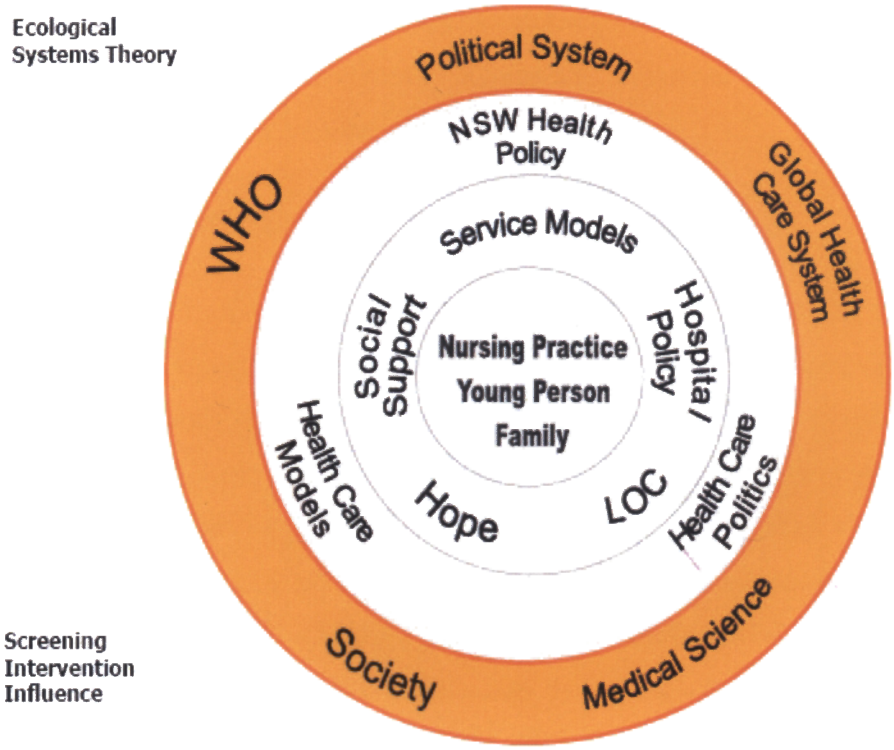

Diagram 4

This level contains the patterning of environmental events, socio-cultural circumstances, and beliefs systems. In my conceptual framework of the healthcare world I have extended this theoretical explanation, or theoretical lens, of the chronosystem to analyse global concerns about the increasing numbers of chronically ill people and the escalating cost of chronic illness healthcare as well as changing healthcare systems and new models of nursing practice in response to these concerns. I have selected literature to focus the discussion on the global advances in medical science that are constantly changing the cost and configuration of illness and health outcomes for the chronically ill and how nurses around the world have responded.

These socio-political circumstances and business viewpoints shape the universal discourse that subsequently drives the way healthcare is organised, funded and accessed by the chronically ill in the more local healthcare world, and, to a significant extent, concomitantly drives the professional lives of nurses. The discussion of the literature in this chapter explores some important changes in the way health care is organised and funded. I also identify opportunities for nurses to participate in healthcare reform as I argue in this chapter that nursing needs to assume a world view on healthcare reform to effectively critique emerging models of service delivery and subsequent nursing practice. This knowledge will enhance the acumen of nursing in healthcare politics and legitimate the profession as a stakeholder and leader in the more local healthcare system.

The Chronosystem: Global healthcare reformations

The globalisation of world affairs is now well under way. This is particularly so in the business of healthcare. Arguably financial markets, trade agreements, political ideologies, information technology and multinational health provider industries are already deeply involved in, and to some extent control, the production of healthcare services around the world. The economic stability and trade agreements of Australia and other nations have direct effects on the Australian healthcare system. Advances in medical science, the global expansion of the pharmaceutical industry, evidence-based medicine and highly skilled clinicians have significantly changed the implications of having chronic illness and will continue to do so (Herzlinger, 2006; Little, 1998). The major factors driving worldwide healthcare reforms that are already having a significant effect on the Australian healthcare system include: the increasing numbers of ageing chronically ill people; the imperative to rationalise the delivery of healthcare resources; the commercialisation of the public health system; the escalating costs of healthcare and the increasing shortage of doctors, nurses and allied health professionals.

New Chronosystems Bringing New Healthcare Models

The landscape of healthcare has dramatically changed in the last 20 years with many ramifications for the professional lives of nurses and the day-to-day healthcare world of the chronically ill. Historically, a life threatening illness has meant, colloquially a 'death sentence' (Livneh, 2001; Malhotra & Singh, 2002; Thorne, 1998). The situation of having a chronic illness as a young person, if one survives, is now vastly different. Recent advances in medical science that can maintain life and relatively healthier states, despite the presence of disease, have dramatically changed the implications of chronic illness. These innovations include transplant surgery, medical imaging, minimally invasive surgery, shorter hospital stays with more care provided in the home, advances in surgical interventions and the rapid growth of pharmaceutical options (Leeder, 1998; Little, 2000; New South Wales Health Council, 2000). A life threatening illness at the present time increasingly means a curable disease, a manageable disability or a chronic illness with an expectation of a return to a meaningful life, albeit for some a shorter life span (Murdaugh & Vanderboom, 1997; Stewart, 2003; Susser, 1990). This century will see developments such as genetic engineering and research into therapeutic cloning, which will again change the healthcare world, nursing practice and the lives of the chronically ill. In this chapter, I argue that, despite continued advances in medical science and the commercialisation of the business of healthcare worldwide, there remain opportunities for innovative nursing leadership and models of care to influence both healthcare reform and health outcomes for the chronically ill.

New Healthcare Models and the Impact on Nursing

Nurses rarely perceive a world view of healthcare; nursing scholarship and evidence for practice reform is limited to the critique of local models of care. The nursing profession remains largely outside the healthcare reform arena (Antrobus & Kitson, 1999; Chiarella, 2002). A world view of nursing and healthcare is important to understand not only emerging trends in the health status of populations but also the efficacy of models of healthcare (Rassin, Silner, & Ehrenfeld, 2006). Therefore, Australian nurses will need a deeper understanding of the healthcare world from a global perspective. With this world view of healthcare service efficacy, nurses could be better skilled to understand how global influences will be expressed in the Australian healthcare system and, how to ensure changes equate to better health outcomes for patients.

A change in the organisation and funding of healthcare has a direct effect on access to and the efficacy of healthcare interventions for the increasing numbers of chronically ill people. Consequently, these changes impact on the capacity of nursing practice to meet the needs of the chronically ill and, subsequently, patient outcomes. In the next section of this chapter, the impact of change as a result of new healthcare models such as managed care and the influence of mixed funding models is discussed, and recommendations made for nursing leadership and practice development to ensure optimal patient outcomes.

Opportunities for Nurses in Change

Nurses in some countries, amidst this changing healthcare world, have begun to develop innovative practice models and advanced skills in response to the ever-increasing demand for chronic illness care. The introduction of managed care during the early 1990s, particularly in the United States of America, has had arguably the greatest effect on health service models and consequently nursing practice. This is particularly evident in the capacity of nursing leadership to influence change in healthcare policy and responsive nursing practice development since the introduction of the medical model (Lubkin & Larsen, 1998).

Managed care broadly refers to a system of payment to second and third parties to provide unit-based care so that specific patient outcomes can be achieved within a predetermined cost, length of stay or prescribed use of resources (Lubkin & Larsen, 1998). Managed care usually involves interdisciplinary teams working with or within insurance groups, employers of large companies, pharmaceutical industries, or private health services. The interdisciplinary teams provide care for many types of illnesses within disease management enterprises or specific illnesses within organisations such as pharmaceutical company-administered healthcare programmes (Waldo, 2000). The patients or members subscribe to a particular company, either by insurance premiums directly or indirectly via their employer, thereby accessing specific predetermined health management services (Lubkin & Larsen, 1998). Managed care programmes evolved in the United States and other countries out of a need to contain the escalating cost of chronic illness care and to control or prescribe patient outcomes (Waldo, 2000).

It has been argued that managed care programs are socially responsive if they have the following eight attributes:

1. Enrolment of a segment of the general population within a defined geographical area
2. Identification and responsiveness to opportunities for community health improvement
3. Collaboration with community-wide data networking and sharing
4. Publication of financial performance and contributions to the community
5. Inclusion of the community in the governance of the program
6. Active participation in health infrastructure
7. Collaboration with academic health centres, health departments and other components of the public health infrastructure
8. Public advocacy of community health promotion and disease prevention policies.

Adapted from Showstack, Lurie, Leatherman, Fisher, and Inui (1996)

The principles guiding managed care programs are established to ensure consumers receive legitimate evidence-based healthcare to meet medical and community healthcare needs. Consumers in the managed care framework are empowered in the decision-making process and are considered to have equitable access to advances in technology and medical science (Showstack, Lurie, Leatherman, Fisher, & Inui, 1996). The intentions of managed care programmes are to provide specific care for the patient's particular health state closer to home and as members of a local community, but within a predetermined cost. Managed care appears to have had varied effects on nursing leadership, practice development, roles in patient advocacy and patient outcomes. In some settings the model of managed care appears to have externalised the control of nursing practice development away from nurses and thus impacted on their ability to influence patient care (Schifalacqua, Hook, O'Hearn, & Schmidt, 2000). In other settings, managed care has created opportunities for nursing governance or at least shared governance arrangements within specific healthcare programmes (Schifalacqua et al., 2000; Storfjell, Mitchell, & Daly, 1997).

Disease management, another way of organising health services developed in the 1990s for the care of specific diseases, evolved out of the vision of managed care. The aim of disease management is to utilise evidence-based medicine and outcome data to improve the health of populations within the community, not to simply control costs (Moran, 1999). Disease management has emerged as an integrated care model with reimbursement based on the natural course of the disease, with a focus on wellness and the prevention of complications

(Moran, 1999). Patients in disease management program are considered active participants in their care. The programmes have an emphasis on self-management and require family support (Moran, 1999). The main criticism of these disease management programmes is the conflict of interest that arises when pharmaceutical companies - with a clear emphasis on profit – are in control. Critics also claim that no real evidence exists that disease management models, within the managed care framework or as stand-alone services, improve outcomes or reduce costs (Bodenheimer, 2000). Bodenheimer believes the principles of disease management are appropriate for chronic illness care but should be integrated within government funded healthcare institutions and primary care services and not outsourced to commercial interests (Bodenheimer, 2000).

Ethical Risks for Patients and the Response of Nursing

There are ethical concerns for nursing in both managed care and disease management models of care that establish a predetermined cost for services and with membership fees enabling access to services. There are warnings that these models of funding and of organising health services delivery, increasingly evident around the world, may risk access and equity to healthcare resources for vulnerable groups (Neff & Anderson, 1995). Children and young people with chronic disease need protection in the competitive marketplace of managed care and disease management. Of greatest concern are children with diseases such as juvenile diabetes mellitus, cystic fibrosis, childhood cancers, and chromosomal and metabolic disorders (Kastner, 2004; Shenkman, Lili, Nackaski, & Schatz, 2005). The complex and expensive care required by paediatric chronic illnesses is difficult to contain and more likely to be excluded or marginalised when profit is the goal (Kastner, 2004; Neff & Anderson, 1995). Cost containment in paediatric chronic illness care may jeopardise the long-term health outcomes, particularly in terms of adolescent physical and emotional development. The early investment of intensive child and family case management focusing on treatment adherence and psychosocial wellbeing and emphasising optimal independence has the potential to lower long-term care costs. Thus, even with the ethical concerns outlined above, there are still lessons to be learned from managed care programs. Such models of care delivery would require thorough assessment if they were to be implemented to ensure chronically ill children are not at risk of reduced access to health care and of poorer health states.

Escalating healthcare costs and increasing numbers of chronically ill have driven considerable change in the American healthcare system. Thus, it is reasonable to expect this situation will force similar change upon the Australian healthcare system. There is an opportunity to learn from international models of care if nurses are willing to assume a world view on healthcare politics and reforms. The biggest challenge for nursing is how to participate in policy and healthcare reform. At present in Australia the industrial movement within nursing represents a strong leadership position for the profession. In NSW, the union movement has achieved great success in improving wages and arguably some conditions for nurses (Holmes, 2005). Although wage increases are important, but in my view, they do not necessarily facilitate a stronger platform to participate in healthcare reform.

The clinical governance domain of healthcare organisations globally situates the nursing profession in a somewhat subordinate position. Healthcare leaders, largely the medical profession and to some degree politicians, do not accept nurses in this level of debate and reform. An international literature review explored factors that influence the ability of nurses to develop innovative leadership roles and nurse-led practice models (Temmink et al., 2000). The findings strongly suggest that many nurses are not conversant with healthcare operations or the process of policy reform. Consequently, nurses are not in a strong position to take up health leadership roles that can influence models of care (Temmink et al., 2000). It is not surprising, therefore, that new models of care and consequential nursing practice development are often imposed and do not occur because of innovative or strategic thinking by nurses.

The 'substitution of care' phenomenon emerging in many new healthcare service models of care has created opportunities for nurses to expand nursing practice, but the move is not without risk for the profession (Temmink et al., 2000). The substitution of nurses or categories of nurses has begun to occur where cheaper health workers (such as nurses) replace more expensive or less available workers (such as doctors). The 'substitution of care' phenomenon is a direct response to expansion of medical technology in patient care, the increasing cost to sustain levels of healthcare and the movement of the point of service away from hospitals and into patients' homes (Scott, 2000). The substitution of care phenomenon in chronic illness health care and nursing practice is found to exist within three clinical contexts: hospital-at-home, integrated care settings and nurses within generalist primary care contexts (Temmink et al., 2000).

I argue that the shortage of doctors has placed nurses in the forefront of multiple clinical milieux, which has in turn created opportunities for nurses to expand practice. However, will these advanced practice nurses just as easily be substituted if they become too expensive or if medical practitioner numbers increase? There may be an opportunity here for nurses to take on leadership roles as advanced practice nurses within the governance of new healthcare models of care and therefore be in a better position to avoid being substituted as market and labour forces change. For this to occur the profession will need to accept that considerable reform formatively in terms of nursing education would be required to effectively prepare the profession to take up roles in healthcare leadership. Attitudinal change is required to prepare nurses not only as clinicians but also as leaders in the politics and business of healthcare services operations.

Changing healthcare arrangements can provide opportunities for nurses to participate in the governance of emerging organisational structures and to achieve more autonomous and clinically responsive nursing practice. Schifalacqua, Hook, O'Hearn and Schmidt (Schifalacqua et al., 2000) describe a model of nursing case management where nurses work collaboratively with a physician as equal partners in managed care contracts for the care of the chronically ill. The nurses in this example provided direct patient care as well as a collaborative case-planning role. The evaluation of this model found that patients had an overall decrease in inpatient length of stay and lower readmission rates (Schifalacqua et al., 2000). Nurse-led services are often integrated within managed care service models and mixed payer systems (proportions of funds from the state and an insurer) (Clendon, 2005; Naylor et al., 1999). Many of these models involve nurses working as discharge case managers from within hospital integrated care teams (Naylor et al., 1999). Evaluation of the Naylor model of chronic illness care reported a significant reduction in readmission rates and total hospital days compared to controls. Naylor et al. (1999) considered that the nurses involved in this scheme had the capacity to cross between hospital and community boundaries, enabling greater continuity of care and efficacy of interventions that cross over contexts of care. Given the position and scope of these roles there may be opportunities within these care models to introduce psychosocial nursing assessment and targeted interventions for the chronically ill, particularly those not coping with their illness or treatment. As these models have resulted from efforts to reduce the cost of healthcare service, the attractiveness of nurse led services to managed care groups can be enhanced if outcomes can be shown to impact on cost.

However, often these innovative roles are limited to larger hospitals with little or no research to evaluate their practice (Hofmeyer & Clare, 1999). The nurse discharge case manager could indeed be part of an integrated hospital and community care team. This positioning of nursing leadership and practice could potentially have a powerful role not only in the transition of patients between the hospital and primary health care, but also between paediatric and adult hospitals. In addition, this sort of service could support patients as they move through different levels of health care, according to acuity and priority of need, within a hospital and between hospitals and community services.

Nurses have broad knowledge of the needs of patients and families across hospital and community services and could be a powerful voice in the configuration of healthcare arrangements, cutting across all contexts of care and illness categories. Wagner (Wagner, 2000), in a literature review of integrated patient care teams working in chronic disease management, found that nurses as case managers are the most successful of all chronic disease interventions. Wagner measured the success of a patient care team across five criteria. These criteria included population based care, treatment planning, evidence-based clinical management, more effective consultations and sustained follow-up. Wagner considered that nurses trained in the additional skills of the clinical and behavioural treatment of chronic disease were the most successful in actually improving outcomes beyond discharge planning. The nurses discussed in this review worked within one or across several primary care practices. Some nurses operated as somewhat independent providers of healthcare, that is nurse practitioners, within services based in disease-specific managed care institutions (Wagner, 2000). However, it is not clear from the literature how autonomous the roles were, what the scope of nursing practice was or what contribution the nurses made to clinical governance within the settings reported within the review.

Opportunities for Nursing to Lead Change

I argue that opportunities will emerge for nurses to be at the forefront of healthcare leadership as the way health care is organised changes, particularly in terms of reducing costs. However, with competing models trying to reduce costs, will nurse leaders be able to continue to uphold nursing values in patient care? Donagrandi (Donagrandi, 2000) argues that nurses taking on roles as case managers are under considerable pressure from managed care organisations to reduce costs, creating ethical challenges about how to provide quality care as well as to meet the fiscal goals of prescribed patient outcomes. Obviously, the achievements of nurses from within integrated care teams can be undermined by the managed care system's need for profit and economically rationalised patient outcomes. This situation would create ethical dilemmas for nurses in providing appropriate, equitable, timely, holistic, and effective care for the chronically ill. This will be an issue particularly for children and adolescents who require a family focus and long-term approach to their care. Nurses will require skills in business leadership but also the courage to stand up and point out the ethical issues emerging in health care to ensure vulnerable groups are not disadvantaged.

A second development in terms of new and emerging models of care has seen advances in medical technology and the pressure of cost containment within hospitals create an impetus for home care organisations to emerge in the healthcare world (Wellard & Street, 1999). Home care for the chronically ill is not a new concept but what is new is the extent to which the level of technology in the home is increasing (Temmink et al., 2000). Again, the level of nursing participation in leadership and governance of these organisations is a distinguishing feature in these new models of care.

Historically, Australia's homecare services have operated from community health centres until the recent emergence of home-based hospital services. Projects by the Prince of Wales Hospital in South Eastern Sydney (Patty, 2000) and Hospital Without Walls (Central Sydney Area Health Service, 1994), predominantly operated by nurses, have established that healthcare at home is less costly than hospital care and results in fewer complications. Home care enables patients to remain at home but it is heavily reliant on significant self or family management, or, for some, the assistance of medical technology and rational funding arrangements.

However, there are still concerns about the efficacy of home care services that, albeit increasingly essential to reduce unnecessary hospital admissions, are costly for hospitals to sustain. Donath (2001) argues that hospital-in-the-home services, unless properly funded, do not achieve real cost reductions but merely cost-shifting between government departments and may not improve health outcomes (Donath, 2001). In Australia, home care nursing services are rapidly expanding, particularly in the private sector. The publicly funded services are under considerable pressure with staff shortages and poor funding models (Viney, Haas, Shanahan, & Cameron, 2001).

Community and home care services may well be the future epicentre of chronic illness care. At present these services have complex and inadequate funding arrangements to meet the ever-increasing demand to provide services for patients of all ages with chronic illness assisted by higher levels of medical technology, people with disabilities and those with mental illness (Viney et al., 2001; Wilkes & Beale, 2001). Nurses often have a major role in the development, implementation and evaluation of home care services as clinicians and/or managers. Opportunities exist in these fledgling services for nurses to take on leadership and management roles to develop effective service models that are not only economically viable but also effectively meet the increasingly technological and psychosocial patient care needs in the home. However, new skills will be required in the business of health care, responsive skill development programs to meet patient needs and management skills for diverse categories of staff.

A model of home care in the United States that is inspiring for nurses considering the challenge of home care services is the Visiting Nurse Service of New York. The New York service is one of four sites participating in a Community Nursing Organisation (CNO). The service is led and governed by nurses under a capitated system of reimbursement from Medicare (Storfjell et al., 1997). The service provides home care and/or community care for enrolees (patients) from specific geographical areas (Storfjell et al., 1997). The CNO has a philosophy of case management and community-focused nursing aimed at controlling the progress of chronic illness, disability, and self-management as well as preventative healthcare services. However, the primary needs of the enrolees are more about providing psychosocial support to help them deal with depression, isolation, and the stress of having a chronic illness (Storfjell et al., 1997). The coordinators believe considerable learning has occurred regarding the potential for nursing governance, the development of specifically targeted screening tools, and opportunities for preventative interventions, even within a fully capitated funding environment. Early findings also indicate improvements in quality of life for enrolees reducing dependence on the service, and the development of specific interventions with a particular focus on psychosocial issues and self-management (Storfjell et al., 1997). The nurse consultants employed by the service have both clinical and fiscal responsibilities for their caseload. The report on this service included little about evaluation within the project; however, the model certainly has potential for Australian nurses concerned about the conflict of interests within managed care endeavours.

The next global issue to be discussed is the impact of technology on facilitating both home based care and ongoing care of the chronically ill. The advent of videoconferencing technology has led the way for healthcare innovations such as tele-medicine and tele-nursing in chronic illness care to enhance access to services in isolated areas and in the home. This area of technology holds opportunities to advance nursing practice development and acumen in chronic illness health care. Demiris, Speedie, and Finkelstein (2001) evaluated the perception of elderly patients of an American nurse led tele-homecare service. The study showed that all 17 patients surveyed were comfortable with the technology and felt confident that the nurses understood their medical problem over the 'tele-screen'. A Swedish hospital managed home care service evaluated a programme for an alternative model of care for stable infants and children with chronic conditions (Berguis et al., 2001). The program involves nurses and physicians providing home care using mobile vans and video-conferencing technology. Over one year the service provided 350 episodes of care for infants at home or closer to home, equating to 3000 bed-days managed by the team. The programme concluded that the model of home care was at least 30% cheaper than conventional hospital care and has now become a permanent service (Berguis et al., 2001). Clearly, technology such as videoconferencing will impact on nursing practice and opportunities for nurses to take up clinical leadership roles in Australia. However, the goal of improving the holistic health outcomes of people with chronic illness needs to prevail, rather than seeing another advance in technology as an opportunity to reduce costs.

The risk with technology in health care is that the technology may become the speciality or the vehicle to reduce costs rather than merely another tool to improve and/or enhance patient outcomes. The potential for tele-medicine in home nursing services in Queensland was examined by retrospectively reviewing 12 630 case notes to determine if the home visits could have been done by telemedicine (Black, Andersen, Loane, & Wooton, 2001). The reviewers considered 1221 of the 12 630 home visits reviewed could have been done using telemedicine technology. The researchers concluded that telemedicine certainly had potential in home nursing in Australia but would need more research and particularly funding arrangements (Black et al., 2001). Research will need to establish whether the application of this sort of technology is simply cost shifting without any perceived benefits to patients.

Video-conferencing has an enormous contribution to make to the education, mentoring and clinical support of nurses in regional and remote locations. My own almost pioneering work in this area has made inroads into the use of technology to support nurses working with mentally ill children across NSW. The nurses can communicate as a statewide network for clinical consultancy, supervision, and educational opportunities (Rosina et al., 2003). There are significant opportunities to extend this model to other areas of nursing to facilitate nurse led services and clinical practice development even in the most isolated locations.

The question of substitution of care, discussed briefly above in the section on changing models of care delivery, will now be further explored. Arguably, the most dynamic and diverse categories of nurses emerging with changing models of health service delivery and the 'substitution of care' phenomena are practice nurses. The role of practice nurses has been implemented in many parts of the world and now increasingly in Australia (McKernon & Jackson, 2001). In many countries, these roles are often part of the ward nursing staff (Cumbie, Conley, & Burman, 2004). In Australia, they are employed by GPs who are given funding directly from the federal government, and they have no award provisions, therefore no career prospects (Southern, Appleby, & Young, 2001). The actual role of a practice nurse remains ill defined and can range from advanced practice nurses to registered or enrolled nurses, working in general or specialist medical practice surgeries. The confusion in terminology used to describe this evolving area of practice has eroded the role boundaries and, in some situations, discouraged these roles both in nursing and the wider healthcare system (Wilson, 1999). There is an argument that the role of practice nurses has simply been a solution to the shortage or position of doctors not wanting to work in particular areas as well as a somewhat veiled argument that, in some areas, nursing is a cheaper option (Wilson, 1999). Advanced practice nurses are uniquely qualified to provide flexible and individually tailored health care to people suffering from a variety of chronic illnesses alongside other health professionals as equal partners (Cumbie et al., 2004). There is overseas evidence that these models of nursing practice are effective in improving health care for the chronically ill and have potential for nurses as equal partners in primary healthcare services (Burman, Cumbie, & Conley, 2003).

There is great potential for practice nurses in health services to work as equal partners but also a risk that will they remain subordinate to the medical profession without a position of influence in healthcare reform. A study by Condon, Willis, and Litt (2000), designed to explore effective shared care between general practitioners (GPs) and practice nurses, used semi-structured interviews across eight practices. The research identified that practice nurses had established effective working relationships with GPs resulting in improved patient care. However, shared governance was not found in any of the practices studied. In this study Medicare reimbursement arrangements were paid directly to the GPs. This situation prevented the development of a 'true shared care' model and, consequently seemed to reduce any opportunities for the practice nurse to participate in governance or to take on any leadership role within the general practices setting.

Evidence of reforms in nursing imposed by governments is increasingly emerging in Australia. In 2003, the federal government announced a plan to recruit 457 practice nurses (Australian Federal Government, 2003). These practice nurses were to be specially trained and placed within general medical practice settings across NSW, possibly where there was a shortage of general practitioners. The question is whether nurses are simply tenuously replacing doctors or whether it is simply an evolutionary process of nurses legitimating primary health care. What remains unclear is the position of practice nurses if doctors choose to return to formerly unpopular areas of medical practice. A second question emerges for the profession – is the nursing profession prepared for this emerging subspecialty or new category of nurse, and will these new positions have a role in the clinical governance of general medical practice organisations? The educational preparation of nurses will need reform to address practice nursing and how the scope of practice for a practice nurse compares with that of a nurse practitioner. Chronic illness health care will undoubtedly be the epicentre of future health systems, emphasising the imperative for the nursing profession to take notice and position its leadership to participate in healthcare reform, particularly where ramifications transform the profession.

Opportunistic innovations in nursing practice to resolve skill shortages need to be carefully considered in terms of risks for the profession and the long-term ramifications. In Australia, one such example that highlights these concerns is the position of clinical assistant created as an extension of the clinical nurse specialist role. Initially, the clinical assistant supported the intensive care unit, and subsequently, the division of surgery, the paediatric ward, and psychiatric wards. The core functions of the clinical assistants are to perform medical assessments, order relevant investigations, arrange consultations with other specialities, provide education, initiate and support research and provide a line of support for medical and nursing services (Balogh & Berry, 1998). The question arises as to whether these roles are truly advances in nursing ideology and practice or whether they are a subspecialty of medicine.

A letter to the editor of Heart & Lung: The Journal of Acute and Critical Care (Schneider, 1999), providing comment on the Australian role of 'clinical assistant', reported by (Balogh & Berry, 1998) commended the innovation and expressed hope for the role of nursing practitioners in the United States. However, Schneider noted the current move away from the traditional caring role of nursing to a more evidence-based practice and technological focus. Further, Schneider added that the new approach to nursing is easily assumed by clinical assistants. If these positions are not integrated within nursing professional structures, the roles should arguably be a subspecialty of medicine within the division of medicine and need to be recognised as such.

There is no doubt that technical advances in nursing practice fill gaps in service delivery where skill shortages emerge. The question arises as to whether these roles are truly advances in nursing ideology and increasing acumen in responding to clinical demands in the healthcare system or these are roles simply a temporary government solution to workforce shortages. The profession of nursing in Australia is increasingly participating in healthcare workforce reforms. This contribution is critical, particularly as the ramifications for the profession are so profound. The clinical assistant, practice nurse, and advanced practice nurse have emerged in response to workforce shortages and have seemingly gained local acceptance and utility.

Significant barriers still exist for nurses to participate as leaders in clinical governance and the leadership of healthcare organisations and, thereby, policy development and reform. The situation has not changed in 30 years, despite the rest of the world changing in almost every way (Porter-O'Grady, 2001). The increased use of technology in health care, shorter hospital admissions requiring fewer nurses and the traditional hospital based healthcare services provided by other categories of staff will no doubt increase and place pressure on nurses to participate in reform. The hallmarks of changes are emerging in Australia, forewarning a move to a more managed care system of health care. Surprisingly, the Australian nursing literature is very quiet about the almost revolutionary changes occurring in health service delivery and nursing practice around the world. For the most part, nurses in Australia appear to be uninformed or unconcerned as global drivers of change begin to emerge in the Australian healthcare system (Chiarella, 2002). Another matter of concern is the fact that the sort of change taking place will have implications for the chronically ill and the professional lives of nurses in Australia. Australian nurses may well be unwilling or indeed unprepared to participate in major healthcare reform. Australian nurses will need to assume a greater global perspective to inform their understanding and ability to participate in healthcare reforms and subsequent policy development. However, there is evidence that Australian nurses are increasingly participating at this level with many nurses participating as co-chairs on

Government Action Plan working parties (The Centre for Research and Clinical Policy & Department, 2000). There is no doubt that healthcare reforms, influenced by global change, are underway in Australia with major implications for current service models and nursing practice. These reforms also hold opportunities for nurses to take up positions of leadership and influence to ensure change actually optimises patient outcomes.

Conclusion

The chronosystem level of Bronfenbrenner's EST has been difficult to analyse and discuss in relation to the world of chronically ill people and the professional lives of nurses, as it is a rarely used component of EST with few studies testing its empirical application. Despite this, it has been useful in my work in identifying the global drivers of change currently reconfiguring the healthcare systems around the world and the professional lives of nurses. Concerns such as the increasing numbers of ageing chronically ill people, the escalating cost of chronic illness healthcare, the ethical concerns about mixed funding arrangements away from the state or federal government health services and the global shortage of nurses and doctors causing substitution of roles are revolutionising the way health care is organised, valued, accessed and funded. This chapter has raised imperatives for the profession of nursing to assume an informed world view on healthcare reform and to consider its position and skills in healthcare leadership if it is to effectively influence a rapidly changing healthcare world.

The analysis of the chronosystem has conceptualised an international stage of healthcare reform and, more specifically, the implications of this stage for nursing. As a result of this analysis, I have argued throughout this chapter that there is a strong and urgent need for nurses to participate in healthcare leadership and reform. However, it is acknowledged that the world stage of healthcare debate and reform has traditionally been the realm of business leaders, politicians and, to some extent, the medical profession, and it will take courage and a new skill if nursing is to enter. Appropriately skilled nurses can then have the opportunity to take up interdisciplinary healthcare leadership roles positioning the acumen of nursing within government, the clinical leadership of healthcare organisations, university faculties and a persuasive voice in the literature – both in nursing and broader healthcare literature. In this way, nurses can influence healthcare reform that has profound implications for the chronically ill and the professional lives of nurses.

In this chapter I have identified the global drivers of healthcare reform, examined new systems of healthcare, critiqued a number of nursing practice models emerging in response to health reforms and put forward a strong argument for nurses to participate in healthcare reform, to take up leadership roles and use an informed world view on health to influence new models of care. In the next chapter, I identify and discuss the outcome of global drivers of change in the chronic illness healthcare world as they are expressed in the more local healthcare world in NSW and the professional lives of nurses.

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Chapter 6

The Macrosystem Level of Ecological Systems Theory:
Nursing leadership in politics and policy

Introduction

In this chapter, I review the chronic illness healthcare policy context in NSW, specifically the ramifications for the chronically ill, and recommend opportunities for nursing to participate in reform. The chronosystem level of the healthcare world was presented in Chapter 4. In that discussion, I identified the major global drivers of healthcare reform, particularly new models of care emerging around the world and the implications for nurses involved in the health care of the chronically ill. I also examined a number of new healthcare service delivery models and the subsequent nursing practice developments that have emerged during the process of healthcare system reformation internationally. I emphasised the risks, but also opportunities, in such models of care for vulnerable patient groups such as the elderly, the disabled, the socially disadvantaged and the children of poor families. I argued that nursing needs to recognise global drivers of change in healthcare, to anticipate how they will shape the local healthcare system in NSW and to take up opportunities to influence change. The effects of healthcare reform will have ramifications for the capacity of nursing, and the interdisciplinary teams in which nurses work, to influence the sort of change that can optimise patient outcomes. The macrosystem contains the culture in which people live: specifically the attitudes and beliefs held by the society, and the perspective of, and resources provided by, institutions and frameworks of social policy within which the society lives (see orange section in diagram 5).

The Macrosystem

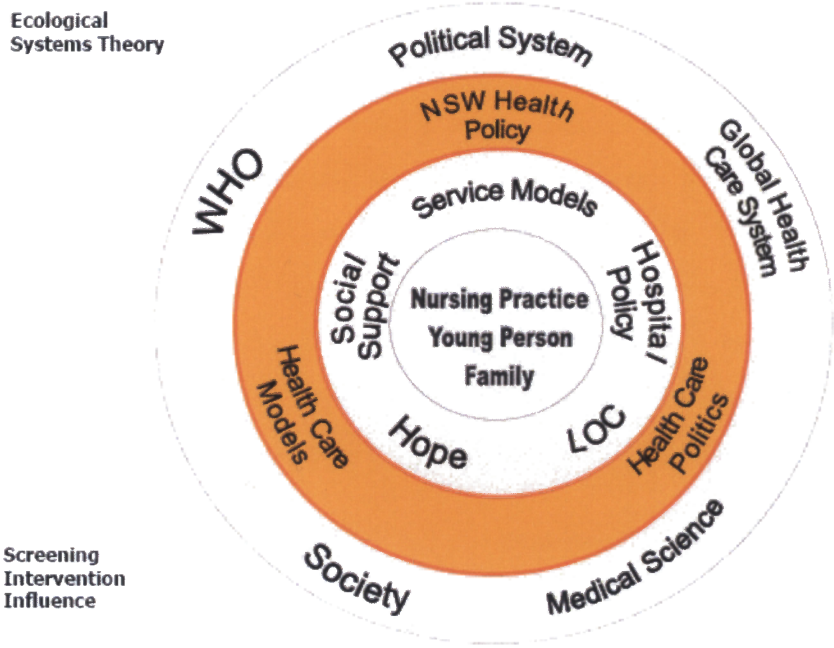

Diagram 5

In my conceptualisation of the macrosystem I have extended this theoretical explanation, or theoretical lens, of the macrosystem to represent the NSW healthcare system, the NSW healthcare policy directions for chronic illness, political decision-making about the care available to the chronically ill and the roles and capacity of clinical nursing leadership activities and models of nursing practice. I have selected literature related to the role of nurses in policy and service reform and specific NSW health policy currently organising healthcare models, containing nursing practice, for this discussion.

Healthcare policy, influenced by global healthcare reforms and local political decision-making, shapes the resources, threats, and opportunities that ultimately lay down the healthcare system for the people of NSW. Simultaneously, other factors in the macrosystem, such as federal government policy, powerful lobby groups, the media, the profession of nursing and consumers, which are highly influential in reform are also explored and recommendations made for nursing leadership and practice.

The Macrosystem

The NSW Healthcare System Response to the Increasing Numbers of Chronically Ill

The NSW state government has begun to implement a number of reforms in response to the growing numbers of chronically ill and the widespread concern about the health system's capacity to care for them as well as patients more generally. In 1999, because of these concerns, the NSW state government established the NSW Health Council. The council was particularly concerned about long waiting lists for elective surgery, overloaded emergency departments, long hospital stays, frequent urgent readmissions of chronically ill patients and the spiralling cost of chronic illness care (New South Wales Health Council, 2000).

The review indicated that the NSW health system performs very well, but there is significant pressure placed on resources by increasing patient demand, particularly in the areas of highly complex and chronic illness care (New South Wales Health Council, 2000). Other concerns related to inadequate continuity of care between hospital and community services, both operationally and in the management of data. Inadequacies in data management were most obvious within patient information systems and the inability of primary care services to access data in a timely way (New South Wales Health Council, 2000). Consequently, many patients with chronic illness have to function as their own medical record and have to undergo the same diagnostic tests repeatedly because their local service provider cannot access results in the required time (Centre for Research and Clinical Policy, 2000). This situation forces patients to endure much unnecessary emotional suffering and, in some instances, significant financial losses.

John Menadue (New South Wales Health Council, 2000), as chairman of the NSW Health Council, in his preface to report stated that he believed that it should have been called the Hospital Council Report as the emphasis seemed to be on sickness, hospitals, more hospital beds and expensive hospital facilities. The NSW Health Council Report was completed in 2000. The document was concerned with developing an action plan to address the escalating cost of chronic illness care and I argue that the report included a rather disconcerting premise that the reduction of hospital admissions would improve health outcomes and quality of life for the chronically ill. The NSW Health Council Report concluded with several recommendations. These recommendations included strategies to improve the coordination of health service delivery for people with complex and chronic illness across hospital and community settings, greater funding for critical care services and for information technology

(New South Wales Health Council, 2000). The NSW government later appointed Clinical Implementation Groups to progress the NSW Health Council's action plan including the first nursing co-chairs. The Chronic and Complex Care Implementation Coordination Group (CCCIG) has identified several key areas for reform. These areas include agreement on health outcomes for the chronically ill, performance indicators to measure outcome, new clinical practice guidelines, and consumer and clinician involvement in treatment and service planning (Centre for Research and Clinical Policy, 2000). The work of the CCCIG is clearly concerned with improving services for the chronically ill but it is also reminiscent of the goals of managed care outlined in the previous chapter.

The first report of the NSW Chronic and Complex Care Program, a component of the NSW Government Action Plan, with its aim to reduce urgent admissions to hospitals and to improve the quality of life for the chronically ill was completed in 2003 (NSW Department of Health, 2003). The results of this project are presented here:

- 20 000 bed days saved due to measurable efforts of CCCIG programs across NSW
- Improved collaboration between general practitioners and other health services
- Consumer engagement in all initiatives
- The development of 'My Health Record' for patients
- The development of a disease-specific state-wide service frameworks and pathways
- The establishment of a disease-specific Priority Healthcare Program within Area Health Services across NSW

The report largely details the progress of 60 Priority Healthcare Programs for people with cardiovascular disease, respiratory illness, and cancer (NSW Department of Health, 2003). The findings, indicating that 20 000 hospital bed days were saved, showed a shift in health care for the chronically ill from the hospital to community-based services. It is not clear from the report how successful the Priority Healthcare Programs have been or if community and home care services can sustain the added pressure on resources without a subsequent increase in resources. There are large gaps in the data returned from multiple area health services or data are simply not returned. The report indicates only 28 out of 60 services had returned information about hospital admissions, re-admissions rates and length of stay to measure the success of the program (NSW Department of Health, 2003).

However, at that stage the project was only two years old, with barriers that included:

- The recruitment, retention of staff and the persistent low morale of staff
- High turnover and insufficient numbers of general practitioners
- Unrealistic time frame imposed on the programs
- Problems with data collection and management infrastructure
- Cultural resistance in changing from existing models of care
- Lack of local ownership of the programs
- Limited resources to implement the programs
- The needs for chronic illness services greater than anticipated
- The training needs of staff greater than available resources
- Funding and capitation problems

(NSW Department of Health, 2003)

These factors have a significant impact on the quality and effectiveness of health care services generally, but specifically in the care of the chronically ill. Despite these barriers, there were a few area health services that did not experience any obstructions and/or any significant difficulties, in embedding the Chronic Illness Care processes into the existing day-to-day work processes of staff (NSW Department of Health, 2003). The programs are now focused on incremental change over time, but great inroads have been made with the identification of barriers to change. At that time the goals of the NSW Health Council for the preceding 12 months had a persistent focus on reducing hospital bed days without the necessary enhancement of community resources or integration of hospital and community services, despite the increasing demand for home care. This situation may be considered as 'cost shifting' activities rather than sustainable improvements in the quality of life for chronically people (NSW Department of Health, 2003). Another issue of concern with this work is the poor return of data making any reforms based on these outcomes highly questionable. However, the barriers to improving chronic illness health care will assist future programs to improve services.

In response to the findings and barriers identified by the NSW Chronic and Complex Care Program, the Chronic and Complex Care Collaborative was introduced as a key activity of the NSW Chronic Care Program (2003-2006) (NSW Health, 2005). The new collaborative continued with the original agenda to better coordinate complex and chronic illness health care but, it has a stronger mandate to improve the diagnosis and management of chronic obstructive pulmonary disease and heart failure. The group has a stronger methodology and a plan for practical incremental changes to clinical systems, enhancement to clinical data collections, improved patient records and the facilitation of targeted clinical skill development to enhance care. Alongside this work and also promulgated by the NSW Health Council, the Greater Metropolitan Transition Taskforce (GMT^2) was introduced to explore and enhance the clinical integration of healthcare services, particularly by networking groups of district hospitals (NSW Department of Health, 2002). This project has had significant outcomes, such as the establishment of 17 stroke units across metropolitan NSW networked to five neurosurgical hubs. The outcome is that these programs will continue to improve systems of healthcare for people with chronic illness and the efficacy of the clinicians who care for them.

Despite the successes of each Complex and Chronic Illness Enhancement program, the increasing workforce problems across the NSW healthcare system have dogged progress and put the sustainability of outcomes in jeopardy. The seriousness of workforce problems across the NSW healthcare system has been identified by reports such as the Health Ministers' National Health Workforce Action Plan (Australian Government Department of Health and Aging, 2004) and the Australia's Health Workforce Report (Australian Government Productivity Commission, 2005). There is clear consensus within both reports that the healthcare workforce needs to extend the skill sets, tasks and responsibilities of healthcare workers in order to create a more flexible workforce, at the same time as they improve service delivery and address shortages of specific areas of clinical services. Policy reforms are reliant on workforce solutions to sustain improvements in quality, service and safety in healthcare.

In addition to workforce issues, the healthcare provided by community and home care services to the chronically ill urgently requires reform. Policy directions rely upon community and home care services but there are a shortfall in comparison to increasing need, which the Department appears not to recognise.

With the advent of day surgery units, outpatient clinics and home care, the chronically ill and their families are now coordinating much of their own healthcare needs. If this situation continues without significant enhancements to community and social services, the current healthcare reforms may well increase hospital admissions and compromise health outcomes for the chronically ill.

Outcome of Reforms

The current reforms in NSW have made some inroads to improve healthcare services for the chronically ill. However, these gains are relatively small and almost impossible to sustain. If significant reductions in hospital bed-days are reliant on sufficient community services to maintain wellness for the chronically ill then it is doubtful benefits will be long-standing. The constant restructuring of the NSW healthcare system has led to a position of stagnancy, stalling effective and sustainable healthcare reform (Braithwaite, Westbrook, Hindle, Iedema, & Black, 2006). Critical debate is required on chronic illness healthcare service delivery but it must be relevant to the health outcomes of young people with chronic illness and must address two major issues. Firstly, agreement is required on measurable psychosocial health outcomes for this relatively new patient group as a framework for interventions. Secondly, considered debate and resolutions need to be made about the ethical and economic dilemmas now confounding the NSW healthcare system. Without resolution of these issues, reduced access to care may be an outcome for young people with chronic illness, particularly children with disabilities, and those from poor families who require expensive treatment regimens. As part of the second issue, agreement is required on what systems of health care and resources will effectively address the contemporary needs of chronically ill people across hospital, community, social and home care services.

Despite the goodwill of initiatives such as the Health Council Report and subsequent action plans, little progress has been made to increase the efficacy and the continuity of healthcare service for young people with chronic illness. The chronic illness healthcare reform initiatives in NSW have a greater focus on specific disease of the aged rather than the broader health and social issues of younger people with chronic illness. This is evident in the latest chronic and complex illness initiative program with its specific focus on diagnosis and the management of chronic obstructive pulmonary disease and heart failure. (NSW Health, 2005). More recently, the Greater Metropolitan Clinical Taskforce (GMCT–formerly GMT^2) has been enhanced to improve health outcomes for young people transitioning from paediatric to adult chronic illness healthcare service. The GMCT has four key outcomes:

1. Consumer involvement
2. Service planning
3. Identification of workforce needs
4. Information management and education.

The challenge will be how to achieve these outcomes given these issues have stalled other chronic illness health service development programs (The Centre for Research and Clinical Policy & Department, 2000). Beyond the achievements of consumer involvement, the identification of gaps in workforce skills and the development of resources, no other evaluation data is yet available.

New Roles for Nurses in NSW Health Care Reform

The situation of continually developing new programs in NSW that are compromised because of the same issues are not being addressed (such as information management, workforce issues, staff skills and education, funding problems and unrealistic time frames) holds back the success of new models of care. Amidst this situation opportunities emerge for nurses to speak with a cohesive voice on these consistently identified barriers to healthcare reform and to suggest solutions to overcome them. In the current climate of nursing and doctor shortages, particularly in rural areas, nursing roles are changing to meet patient needs. The situation raises the opportunity for nurses to consider nurse led services rather than having government solutions and new models of care imposed on them.

When the NSW Health Council Report was released in 2000, it addressed the issue of new roles for health professionals in response to workforce shortages. The NSW Healthcare Council Action Plan proposed the role of a case manager to coordinate complex and chronic illness care (The Centre for Research and Clinical Policy & Department, 2000). The case manager would coordinate the monitoring and management of chronic illness and cancer patients. More specifically, the case manager would coordinate the timing of pathology tests, treatment changes, clinical reviews, and hospital admissions. There are opportunities within this model to develop an efficient and effective nursing service working in shared care arrangements with primary health providers. The nurse case managers would develop a disease management plan incorporating hospital and community care for each patient, including routine health screening, preventative health education, serial psychosocial assessments, and appropriate referrals.

The NSW Health Council Report recommended the promotion of case manager positions in all public hospitals (New South Wales Health Council, 2000). Nurses in these roles have the opportunity to participate in health service reform by developing models that connect community and hospital services. However, the issues of Medicare item numbers for reimbursement and policy to support the practice are still not resolved (McKernon & Jackson, 2001).

Practice nurse positions, another federal government initiative to enhance primary care services, are beginning to increase in Australia. Practice nurses are currently employed by GPs. This collaboration could have enormous benefits for patients with chronic illness, particularly in the provision of care closer to home and in their local communities. The advent of video-conferencing and the electronic health record accessible to the entire healthcare team would make a significant difference to the lives of people with chronic illness, particularly in rural areas. Rural populations are frequently reported to have less access to health care and generally a poorer health status than their city counterparts (Edward, O'Briena, & Bailie, 2000; Wilkinson & Cameron, 2004). An innovative nurse led service incorporating shared care with GPs and tele-health services would be an attractive model for governments to consider.

The employment of practice nurses is well under way in Australia. A survey of Australian GPs working with practice nurses explored the capacity of and barriers to the notion of 'sharing care' with nurses and other health professionals (McKernon & Jackson, 2001). Many of the GPs identified the cost and lack of a Medicare item as the major disincentives to 'sharing care' with practice nurses. The majority of GPs accepted the potential of practice nurses and other health professionals within an integrated care model but considered that funding, legislative and policy issues would need to be resolved (McKernon & Jackson, 2001). It may be that nurses as business partners with doctors need to work through the historical issues of nursing being subordinate to doctors.

Practice nurses are ideally placed to coordinate the care of patients with chronic illness and they have a direct influence on and role within the clinical governance of services. The stepped-care model of shared care between GPs and practice nurses may be the answer to providing continuity of care and a rational use of resources (Katon, Von Korff, Lin, & Simon, 2001). Stepped-care models are based on three main assumptions: different people require different levels and configurations of care, the movement of patients between levels of care needs to be continually monitored, and there must be measurable outcomes. This approach increases the effectiveness of care and reduces overall costs (Katon et al., 2001). In the stepped-care model, GPs are involved with medical specialists in making the initial diagnosis of the disease and the initiation of treatment. Practice nurses in this model are involved in providing education, monitoring treatment adherence, behaviour therapy, active followup and outreach services to patients to improve and measure outcomes. Medical specialists provide consultation services and supervision to GPs and nurses, particularly for more complex cases. Practice nurses in this model of care would have the opportunity to monitor and to develop measurable outcomes of psychosocial health and quality of life.

The Australian federal government has recently released a Medicare Plus policy. This policy pledges additional funding for 1600 full-time equivalent practice nurses by 2007 (Costello, 2005). The nursing positions would support the work of GPs in general practice by providing services such as immunisations; well women and well baby clinics; prenatal and postnatal clinics; asthma, diabetic and heart health education; wound care and general health counselling. The initiative is in response to the decline in Medicare bulk billing across NSW and the shortage of GPs in rural and some regional areas. Whilst practice-nursing initiatives have in the main been well received by doctors and patients, if doctors return to previously unattractive general practice or funding arrangements change, what impact will this have on these new nursing positions? The brief of these new nursing positions, specifically the goals of improving the integration care across hospital and community settings, may not be addressed in this model. The policy also states that these nurses would be under the 'broad supervision of GPs' (Costello, 2005). Again it is unclear what this means for the profession of nursing in terms of clinical accountability and professional support for the nurses.

The Medicare Plus government initiative has been largely organised outside the nursing profession but has significant ramifications for the profession. The Australian Nursing Federation, in response to comments by Federal Minister Abbott and the Medicare Plus reforms, stated that the number of undergraduate places would need to be increased to meet the target of 1600 practice nurses. Further, financial incentive would be required to attract and retain nurses in nursing positions (Illiffe, 2003). It is not clear how much influence nurse leaders in NSW have had over the plan to appoint these practice nurses, but perhaps it is little in light of the comments by the Australian Nursing Federation and the absence of other comments from nursing at the time. These nurses may become separated from mainstream nursing or perhaps become a sub-speciality of medicine. The practice nurse model may well become a retrograde step for the nursing profession if nurses do not participate in these reforms. With the proposed funding, it is likely that practice nurses will work in collaboration with GPs but without the direction and support of the nursing profession. On the other hand, nursing could step forward, take control of nursing workforce reform, and propose another model for practice nurses, one with more autonomy, an equal position in governance structures and imbedded within the profession. However, this is a federal decision but there is no chief nursing officer at this level to give a voice to nursing

Nursing Leadership and Nursing Reforms in NSW

The nursing industrial body, probably the most powerful and effective voice for nurses in NSW, has had considerable success increasing the salaries of nurses. However, higher salaries may not be the highest priority to attract and retain nurses in the profession. The Nursing Practice and Process Development Survey 2002/2003 showed that, of 2043 responses to a question about what factors assist in providing quality nursing care, only three respondents considered adequate pay an issue (NSW Ministerial Standing Committee on the Nursing, 2003). It was found that the majority of nurses reported that job satisfaction, adequate staffing and good leadership were higher priorities than higher salaries (NSW Ministerial Standing Committee on the Nursing, 2003). These findings suggest that nursing requires another platform for reforms to address those issues nurses believe require resolution and that result in changes that retain nurses in nursing.

Information about the structure and efficacy of nursing leadership in NSW set apart from the industrial agenda is difficult to find. Notwithstanding the importance of improving the salaries and conditions of nurses, the profession needs to come forward with a more informed nursing strategy, not only to develop the profession further but also to participate in healthcare policy debate and reform. The tasks before the profession in NSW include the development of a more influential and participatory leadership model at state and federal levels. The challenges and problems that underpin these tasks include the current workforce panacea of replacing nurses with lesser skilled non nursing personnel, the emergence of nurse practitioners and understanding why they are struggling to be employed, the dismantling and disempowerment of Clinical Nurse Consultant positions in patient care and the urgent need to position nursing acumen, together with the views of consumers, at a political level.

The creation of the chief nurse position in the NSW Department of Health has been a step forward for nurses in NSW as a voice to contribute to debate and reforms. The department, after much lobbying by senior nurses, established the position of the chief nurse in 1989 (Meppem, 2003). At the time, nursing urgently needed a nursing presence at the senior executive level of NSW Health to work with government to find solutions for the significant nursing vacancies and the increasing workloads of nurses (Meppem, 2003). However, the role may not carry sufficient power to influence or lobby the government on behalf of the profession. Meppem, in her reflections on 12 years of service, remains convinced that the absence of nursing in political debate is due to antagonistic elements within the medical profession that undermine nursing input into policy determination (Meppem, 2003). This situation seems to stall any further efforts for the profession to raise itself as an integral player in healthcare debate and reform. The oppression of nursing generally by the medical profession, particularly towards leadership roles and activities within healthcare services, is not new. Medicine, as a discipline, may not be the only barrier blocking the profession from participating at higher levels of the healthcare system. I argue that the medical lobby in itself is not powerful enough in politics to prevent change but, by its sheer single presence in providing advice to politicians, it is consequently the only voice heard. Nurses need to participate more fully as government advisors on policy matters but they will need new skills in policy development and healthcare leadership. I explore the capacity of nursing leadership and leadership strategies more fully in Chapter 9.

Conclusion

In this chapter, I have identified and discussed the major policy directions in NSW targeting an improved healthcare response to the challenges of chronic illness health care. The aim of these policy reforms is ethical, effective, and sustainable healthcare delivery for the increasing numbers of chronically ill people. Current health system reforms bring about short-term solutions, cost shifting and small gains in the organisation of healthcare services for the chronically ill: the repertoire of NSW health reforms. The issues that need to be addressed includes workforce shortages; escalating healthcare costs and service demand; fragmented and limited policy research; overlapping and opposed federal and state government jurisdictions; a disenfranchised and eroded nursing profession with a blunted sphere of influence on policy reforms; increasing pressure to commercialise and privatise NSW healthcare services; and lack of opportunity for consumers to participate in healthcare debate and reforms. However, without addressing the underlying problems that plague the NSW healthcare system, the standard and accessibility of public health services may be compromised.

I have continued to argue that the profession of nursing can be a highly influential group in health care. However, this will require a shift in emphasis for the profession from an operational point of reference in healthcare governance to a position of strategist and leader. The profession will require a new image. Nurses need to be defined as healthcare leaders with significant acumen in healthcare reform. The popular public view of nursing, which historically has been the profession's greatest supporter, needs adjust to the role of nurses as healthcare leaders influential in reform, as clinical experts and as scholars in the modern healthcare world (Antrobus & Kitson, 1999).

The ultimate healthcare system laid down for health service consumers in NSW is a result of a combination of activities that include global influences, the manipulation of healthcare resources in NSW by politicians influenced by advisers such as healthcare service leaders. However, despite the amazing progress of medical science leading to improved rates of survival from chronic illness the organisation of the healthcare system, on which patients rely, is frequently inefficient, ineffective, complicated, for some difficulty to access, and not user-friendly (Herzlinger, 2006).

Healthcare reforms that re-organise service delivery models have flow-on effects to the efficacy of clinicians and consequently patient outcomes. In particular, they affect the capacity of nurses and interdisciplinary teams to meet patient needs in a way that optimises biological and psychosocial outcomes. The profession itself, under the guise of medical opposition, is a weak player in healthcare politics, specifically in using nursing leadership to influence healthcare reform. Clearly, nursing will need skills to participate at this level of healthcare politics.

This discussion is continued in the next chapter but takes a slightly different turn. Nursing scholarship is integral to clinical leadership and clinical leadership activities. The interlinking roles of the exo and meso systems, within my conceptual framework, use nursing scholarship, about how young people cope and adapt to living with chronic illness, to influence policy reform and service model development at the macrosystem level and to optimise the interaction between the internal world of young people and nursing practice at the microsystem level. The next chapter will present the exo and meso systems of the EST framework.

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Chapter 7

The Exo and Meso Systems: Extending nursing practice scholarship

Introduction

The theoretical analysis in my thesis is continued in this chapter presenting the exo and meso systems of Ecological Systems Theory (EST) (see orange section in diagram 6 below). I present the exo and meso systems together, in this chapter, because the systems and contents of each system often overlap making it, at times, difficult to distinguish actions and outcomes within the context of a young person with a chronic illness in an adult hospital (see orange section in diagram below). EST holds that the exosystem contains social settings where the individual does not have an active role but outcomes have an indirect outcome on the individual's developmental outcome. The exo system outcomes influence up to the macrosystem and down to the meso system. The exosystem contains the social environment, family members, the neighbourhood, the media, social and healthcare policy, and the associated services for individuals (Bronfenbrenner, 1979). In my conceptual framework, these settings become the adult hospital setting, service models, nursing clinical leadership activities and nursing practice scholarship.

The meso system connects the outcomes of interactions within the exo system to the microsystem. The individual is more directly impacted upon and influenced by outcomes within the meso system. Within EST the meso system contains family experiences, school or work experiences and peer experiences interacting directly with, and acted upon directly, by the individual. In my conceptual framework the meso system contain frameworks for nursing practice. The important theoretical understanding about these two levels of the framework, containing these interlinking (exo and meso) systems, is the bi-directional capacity across the levels of EST, particularly strong within these systems, to influence up to the macrosystem and down to the microsystem – informing healthcare policy and nursing practice to optimise patient outcomes.

The young person is indirectly influenced by the acumen of nursing scholarship within the exo system informing frameworks for nursing practice within the meso system aiming to improve coping skill development and adaptation to chronic illness (measurable in the microsystem). The individual in EST is not a passive recipient but someone who, given optimal experiences can utilise environmental factors, such as responsive nursing and interdisciplinary practice, to develop skills to cope and adapt to living with chronic illness. This theoretical analysis expands nursing scholarship by including a deeper understanding of coping theory and coping skill development, to inform frameworks nursing/interdisciplinary practice, for young people with chronic illness in an adult hospital.

The Exo and Meso Systems

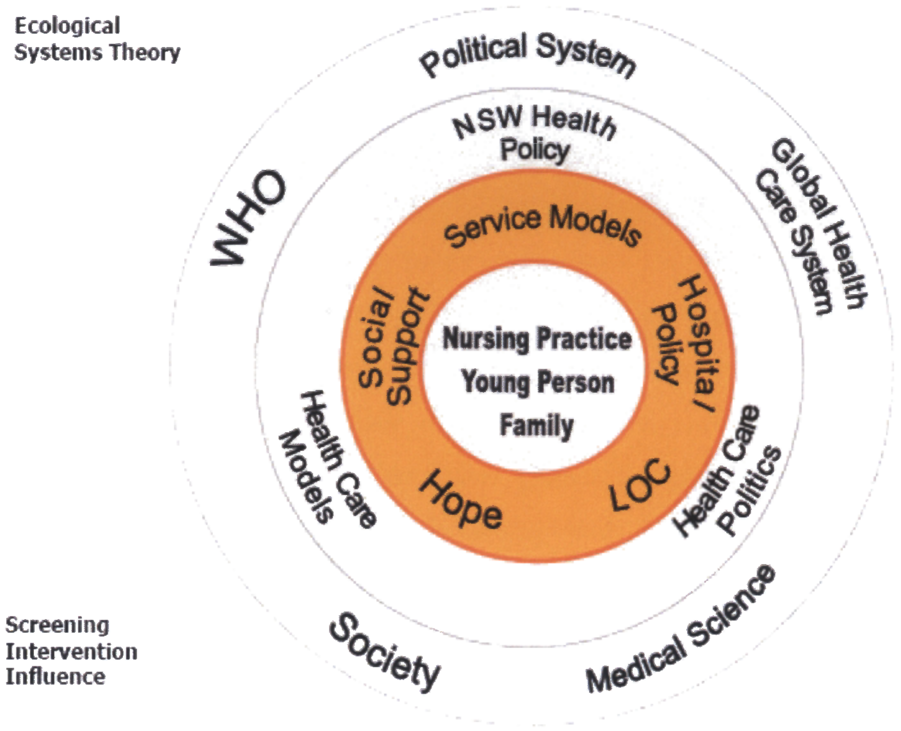

Diagram 6

Why I have Chosen to Expand Knowledge about Coping

Given the findings and issues identified in both the clinical problem/clinical situation analysis and the literature review, as well the struggles and problems for young people with chronic illness identified in the empirical study, I decided that more knowledge was needed about how this group cope and adapt to chronic illness. My primary aim in this chapter is to expand knowledge about coping skill formation and the frameworks necessary if nursing practice is to provide opportunities for the development of coping skills in day-to-day healthcare. I have selected specific literature, often seminal work, to provide a theoretical analysis of the development and identification of coping skills. I then apply this knowledge to better understand coping skill development for young people with chronic illness. Recommendations are developed for nursing practice, and the contribution nursing practice can make to interdisciplinary healthcare interventions in order to increase opportunities for the development of coping skills for this group.

Exo and Meso Systems Represented by Clinical Leadership Activities and Nursing Practice Scholarship: Bi-directional drivers of change

The positioning of nursing practice, 24 hours a day seven days a week including ongoing contact with patients and families in the community, creates an environment or context where nursing practice and the role of nursing practice within interdisciplinary teams can influence responsive healthcare. I argue that clinical leadership, nursing scholarship and frameworks for nursing practice aimed at better coping can improve psychosocial health outcomes for young people with chronic illness as well as more responsive policy development. Clinical leadership and nursing scholarship, informing frameworks for nursing practice, in my conceptualisation, become the linking factors connecting each level of framework and thereby optimising patient outcomes. Clinical leadership and nursing practice scholarship act in a bi-directional manner to inform upwards to the level of policy reform and downwards to inform frameworks for nursing practice development, the interaction of nursing practice in the internal world of the young person/family and patient outcome

New knowledge about coping and adaptation to chronic illness as a young person

Despite the increasing number of people affected by chronic illness and the mounting research evidence raising concerns about their psychosocial health, very little can be said to have had an impact on psychosocial nursing practice development from a policy, clinical or research perspective (Eiser, 1993; Marshall, Fleming, Gillibrand, & Carter, 2002). This is particularly evident within the context of the clinical problem that is central to my work in the adult context of chronic illness care. I have argued in previous chapters that healthcare policy needs to be more responsive to the psychosocial needs of young people. I aim in this chapter to address these gaps thereby effectively connecting the macrosystems to the microsystem via the exo and meso systems in my conceptual framework or, in other wards, nursing scholarship to policy development and to patient outcomes.

The Process of Coping and Adapting to Living with Chronic Illness

I hypothesise that several components (or skills to enable coping) in some way interrelate and combine to enable the process of coping:

1. Psychosocial developmental mastery
2. A sense of coherence
3. The trait of resilience
4. Locus of control
5. The utility of social and familial support
6. The strategy of normalising illness
7. The role of hope in adversity.

How people cope and adapt to a life threatening and/or chronic illness is as varied as the individuals experiencing it. Biological, psychological, social and existential factors converge into a unique response to the diagnosis of illness, the impact of treatment, the level of impairment and the ultimate outcome of treatment. The affective response to the predicament of illness has a direct effect on the capacity to cope and the process of coping. The ability or strategy to cope with illness related adversity is identifiable as a coping strategy or coping style (Rifkin, 2001; Slaby & Glicksman, 1985). A multitude of factors related to the disease itself, to the individual, to the characteristics of the family as well as social factors underpin the seven components of coping, the process of and effectiveness of coping efforts (Daum & Collins, 1992; Erikson, 1963).

The process of coping begins with the emergence of symptoms, the experience and the uncertainty of investigations to identify the disease, followed by the treatment. Young people then try to adjust to the impairment and to the impact on their day-to-day life. Each time the presentation or level of illness changes, the configuration and re-configuration of symptoms and impact on day-to-day life changes for the young person and the family. Chronic disease research into treatment and cures, specifically drug treatment clinical trials, are prolific in the world of chronic illness healthcare, with families anxious for the latest and most effective treatments. As each new treatment is offered to patients, a re-configuration of the illness and impairments occurs, as well as a re-appraisal of coping and personal resources.

The Stressor of Diagnosis and Impact on Coping Skills

The discovery of having a life threatening illness and/or living with chronic disease is a significant point of crisis and a life event stressor for individuals (Hymovich & Hagopian, 1992). The diagnosis of chronic illness during the developmental period of adolescence is a particularly stressful event as young people strive for acceptance by peers and begin to individuate themselves from their parents. For some young people diagnosis is made at birth, with the crisis and the challenge of coping more an issue for parents. For others a later point of crisis may occur when the true psychosocial impact of the disease can be fully appreciated by the child and brings another stage of grief and loss for their parents (Hymovich & Hagopian, 1992). This crisis point may occur on entry into the school system while young people are interacting and comparing themselves with their well peers. The developmental challenge of adolescence for young people with chronic illness is further complicated by the fact that the illness may still demand a level of physical and emotional dependence on parents and healthcare services (Hymovich & Hagopian, 1992).

The developmental and situational stressors experienced by chronically ill young people and their families may strain or exceed their ability to cope (Hymovich & Hagopian, 1992). Particular stress points of psychosocial vulnerability exist during the course of the illness. These particular stress points may be triggers for psychosocial assessment and interventions. The complexity of predicting points of vulnerability cannot be underestimated. A greater understanding of the coping process and stress points can identify young people who are not coping and allow for intervention early in their distress. Further research in this area may provide some predictive modelling of stress points and of those more likely to become distressed.

Understanding Coping

I present the analysis and discussion of how young people cope and adapt to living with chronic illness at two levels, consistent with my theoretical framework. I have represented the exo and meso systems as the environmental factors of clinical leadership, nursing scholarship and frameworks for nursing practice. I have chosen to discuss the meso system first as it orders the coping discussion in a more meaningful way. That is, from what makes up a young person's capacity to cope and what factors beyond the young person, such as family and nursing care, influence the development of coping skills. This section of this chapter will now bring together the literature and my contribution to the discussion structured around the seven components of coping that I hypothesise enables the development of coping skills.

Overview of the Coping Process

Seminal work by Lazarus examined stress appraisal and coping among the Israeli people enduring war and threats to their own personal safety and their nation's security (Lazarus, 1982). Lazarus established that coping activities are crucial mediating processes in the stress emotions and the capacity to adapt to new, threatening and or changing environments. In response to situational threats and crises, each individual is considered to have a coping potential. An individual's coping potential is measured by their ability to sustain a viable person-environment relationship whilst experiencing a stressful encounter (Lazarus & Folkman, 1984). Young people with chronic illness are confronted in a similar way as Lazarus' subjects with a sudden threat or a sense that the world is becoming more uncertain with the threat of illness in their lives.

Coping consists of the cognitive and behavioural strategies pulled together by the individual to manage specific external or internal demands. These demands are determined as challenging to the individual requiring a coalition of personal resources (Lazarus & Folkman, 1984). Coping can be conceptualised as a process of bringing together cognitive and behavioural strategies and deciding to what extent the stressful encounter can be managed, and what resources will be used (Lazarus, 1991; Lazarus & Folkman, 1984). The way individuals cope, or potentially how nurses can identify coping abilities, is referred to as a coping style (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002). Each individual, confronted with a life threatening illness, mobilises different defences to adjust to illness stressors (Slaby & Glicksman, 1985).

In seminal work by (Folkman & Lazarus, 1988), coping strategies or styles have been categorised into three groups – emotion-focused, problem-focused and appraisal-focused coping. Subsequent researchers have defined each of the three coping strategies or coping styles (Sarafino, 1990; Sundeen, Stuart, & Rankin-Desalvo, 1989). An emotion-focused coping style is the situation where individuals try to process their emotions by acting on emotion and thinking about their predicament as connected to the emotion. Problem-focused coping is a situation where the individual believes they can change or modify the stressor of the disease or that they can utilise their personal resources to defend themselves. Appraisal–focused coping implies that the individual mobilises a cognitive process of appraising the situation or the stressor and then makes a choice of a coping strategy to deal with the stressor (Lazarus, 1991; Sarafino, 1990). Continuous appraisal of the threat, and the process of mobilising a coping strategy, occurs in order to re-configure and adjust to the changing relationship between the internal world and the environment (Lazarus, 1991; Sarafino, 1990).

Attempts to cope focus on three distinct stressors:

1. The presence of the disease itself

2. The ramifications of the disease for physical and psychosocial functioning

3. Feelings about the illness and the implications of treatments (Verwoerdt, 1972).

Coping abilities can never be taken for granted regardless of the illness prognosis or the current level of stress. An early appraisal of coping can recognise individual vulnerabilities, strengths and current coping capacity. This early appraisal of coping capacity can lead to a more responsive nursing intervention to facilitate coping. Research is needed to normalise assessments and interventions targeting coping skills into mainstream health care, rather than the current situation of waiting for poor coping to be identified as treatment adherence problems or being a 'difficult adolescent'. There is great potential for coping styles and coping resources to be identified and assessed in routine nursing practice with further input from other disciplines. Given that environmental resources can improve coping skills, nursing interventions could also enhance this process for young people and families.

The personal resources vital to the process of managing stressful encounters are considered as constituents or antecedents to the coping process (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 2000; Lazarus & Folkman, 1984). The ability to cope is not static; at each stress, point or stressful encounter the individual's personal resources are appraised and re-appraised and the process of coping or possible outcome of coping is re-configured (Lazarus, 1995). Earlier in the chapter (p114) I hypothesised that there were seven interrelated components of coping. These components are now discussed in detail below.

The Components of Coping

1. Psychosocial developmental mastery

The literature is persuasive in its belief that psychosocial developmental mastery is a critical element of one's capacity to cope with adversity (Brown et al., 2000; Erikson, 1968; Hornsten, Norberg, & Lundman, 2002; Johnson, 1999; Lazarus, 1991, 1995; Madden, Hastings, & Hoff, 2002; McCauley, Feuillan, Kushner, & Ross, 2001; Meijer et al., 2002). Research, by case study analyses, has explored coping and adaptation to living with a cancer related illness amongst young adults with cancer (Daum & Collins, 1992). The researchers found that the successful resolution of adolescent developmental tasks was a strong predictor of more positive coping and adaptation to a cancer diagnosis. The integrated structure of the human personality is a result of the successful development and integration of a sense of self, critical to the process of coping (Erikson, 1968). Daum and Collins concluded that unresolved developmental conflicts about intimacy, trust and dependence may be re-enacted later in life, particularly at times of distress, and impede efforts at coping with illness related threats to life and on life opportunities (Daum & Collins, 1992).

The relationship between psychosocial developmental task mastery and coping with chronic illness was tested by a recent qualitative study. Ten people with diabetes were interviewed about their memories of life at points of critical psychosocial development mastery (Hornsten et al., 2002). The interpretive process used in the study showed that the critical developmental tasks related to coping skills were trust, identity, and integrity. The ability of children and adolescents to cope with illness seems to be reliant on the mastery of significant psychosocial developmental tasks during adolescence.

2. A sense of coherence

A sense of coherence is considered to be a powerful mediator of coping (Antonovsky, 1996). The development of a sense of coherence is reliant on the successful resolution of the developmental task of achieving a sense of identity and a perception of a meaningful role in the society (Grotberg, 1994). The sense of coherence concept is composed of three elements: comprehensibility, manageability and meaningfulness (Antonovsky, 1987). An individual with a strong sense of coherence believes that the stimuli within the internal and external worlds are structured, predictable and explicable. A sense of coherence creates a belief that the available personal resources can meet the challenges of stressful stimuli and that they have meaning (Antonovsky, 1987).

Seminal research by Antonovsky et al. was conducted to explore why some World War II concentration camp survivors were well adjusted and adapted to life after prolonged trauma in the camps whilst others had poorer health and psychosocial functioning (Antonovsky, Maoz, Dowty, & Wijsenbeek, 1971). The research findings established an underlying personal quality found amongst well-adjusted survivors of the camps. These individuals had a protective personal quality against adversity, later identified as a sense of coherence (Antonovsky, 1993). A sense of coherence is thought to develop during childhood and adolescence, becoming a relatively stable personality trait (Antonovsky, 1979).

The identification and measuring of a sense of coherence has remained fairly elusive and challenging to clinicians. A quantitative study of five groups of healthy people and eight patient groups measured the sense of coherence amongst the groups (Langius & Bjorvell, 1996). It was found that a weaker sense of coherence correlated with higher self-rated anxiety, functional limitations and a more severe perception of symptoms in the patient groups (Langius & Bjorvell, 1996). The development of a sense of coherence is thought to be incremental, slowly forming over childhood, adolescence and young adulthood and then becoming relatively static in adulthood. Antonovsky's theory maintains that an individual's sense of coherence becomes stable by the end of young adulthood and is only influenced thereafter by major life events or crises, albeit providing a very brief window of opportunity (Antonovsky, 1987). Later work exploring the formation of a sense of coherence has identified that, at specific points of considerable distress during an illness trajectory, there potentially may be opportunities for further development of the young person's sense of coherence (Hymovich & Hagopian, 1992; Kyngas et al., 2001). Nursing interventions can take advantage of these windows of opportunity to strengthen the young person's sense of coherence.

Potential nursing research and practice development for young people with chronic illness can be clearly drawn from and underpinned by Antonovsky's theory. Nursing interventions can strengthen the sense of coherence for young people facing life threatening disease and chronic illness. Given the consumer demand for health outcomes that include the defining components of a sense of coherence, nursing research programs in this area would be clearly inspiring for nursing practice development.

3. The trait of resilience

The effective use of coping skills is reliant on an ability to 'bounce back' after recurrent adverse events. What is hard to understand is why some young people cope with often-serious illness adversity without any significant impact on them personally, whilst others, with seemingly less adversity presented by an illness, succumb to extreme adjustment problems. The presence of resilience seems to act as a buffer facilitating some people to cope and adapt to adversity and even to experience personal growth following adverse events (Jacelon, 1997). Resilience is a complex construct. It is frequently referred to as both a trait and a process, utilised by individuals to 'bounce back' from and cope with stressful life events (Dyer & McGuinness, 1996; Kadner, 1989; Rutter, 1987). The presence of resilience as a personality trait is considered to enable children to mature and has a distinct role in the enhancement of psychosocial developmental competencies, despite the experience of adversity (Gordon Rouse, 1998).

A criticism of Bronfenbrenner's ecological systems' theory is that it fails to take into account the 'degree of embeddedness' of the individual into their environment (Sternberg & Grigorenko, 2001). I have not explored this criticism to any degree within my thesis, but the concept of how 'embedded' a person is in their environment may influence to what degree the environment influences the individual. This notion is a different area of study and depth of discussion which could lead me away from the key quest of my thesis. However, I make note of it here to acknowledge that it may have potential relevance as to why some young people 'bounce back' from the stressful life events associated with chronic illness and others do not. The aspect in this discussion is that the personal factor of resilience may be important to the process of 'bouncing back' after stressful life events. It is acknowledged that the presence of resilience may be influenced by factors such as the degree of 'embeddedness' in one's environment, which may influence the development of resilience.

The questions for this section of the thesis are how to develop this ability in individuals who are less resilient and what makes up resilience. A classic 40-year longitudinal research study has attempted to answer this question with a multi-racial cohort of all children born in 1955 living on a Hawaiian island who demonstrated a number of protective factors that preceded the trait of resilience (Werner, 1997). The children were exposed to poverty, perinatal stress, parental psychopathology and family discord. Resilient children were found to be able to engage with other people, had good communication and problem solving skills, and were able to develop affectionate ties that encouraged trust, autonomy and initiative. The community surrounding the resilient children had positive role models that reinforced the development of psychosocial competencies (Werner, 1997). This study provides evidence, albeit in a different context, that the capacity of resilience can be developed in children despite their being under great stress. In the context of this study the development of resilience, despite biological abnormality or environmental obstacles, was possible with the right environmental factors to enhance coping resources. The compelling question is what are the right environmental factors required for children and adolescents to develop resilience whilst enduring illness related adversity?

The renowned Werner study has provided a greater understanding of what makes up the personality trait of resilience. The study established convincing evidence that there is a cluster of characteristics common to resilient people (Werner, 1997). These characteristics include the ability to elicit positive responses from caring people, the possession of skills and values that assist them to use their own abilities, good social skills, strong reasoning abilities, significant strengths in autonomous functioning, some androgynous characteristics, sensitivity to the emotions of others and an internal locus of control (Werner, 1994). The researchers believed that the potential to develop these characteristics at each developmental level is possible. The ability to care for others may be nurtured but other characteristics of sociability may be innate. The total capacity to develop good social skills may be present at birth and not so amenable to development (Gordon Rouse, 1998; Werner, 1997). Rutter suggests that the development of resilience may be enhanced by previous positive coping experiences (Rutter, 2000). Many of the elements that compose resilience are definable and to some extent measurable, but how to facilitate resilience is perhaps less understood, particularly in nursing, and will require research.

4. Locus of control

The notion of locus of control may well be another element in the coping process. Pioneering work by Rotter, with its origins in social learning theory, identified the notion of a locus of control (Rotter, 1954). The construct of a locus of control refers to the extent to which a person believes that their own actions influence events in the world. Individuals with a strong internal locus of control believe that their success or failure is due to their own efforts with outcomes under their personal control (Rotter, 1954). Individuals with an external locus of control have a belief that life events are controlled by luck, chance or powerful others. However, Rotter emphasises that locus of control is not a typology and there are degrees of internal and external loci of control. These variations are related to an individual's learning history of expectations about the capacity to control life (Rotter, 1954).

Later contributions to Rotter's theory have orientated the concept toward health locus of control whereby individuals have a belief that their health is controlled by internal or external factors (Wallston, Wallston, & DeVellis, 1978). Health locus of control, a dimension of locus of control, refers to the extent to which individuals believe that they can control their own health and, in turn, quality of life (Wallston et al., 1978). Health locus of control is pertinent to understanding how children, adolescents and their families cope and adapt to chronic illness. A number of studies have reported that health locus of control among children and adolescents with chronic illness is affected by a number of factors including age, developmental mastery, socioeconomic status, gender and the nature and severity of the illness (Perrin & Shapiro, 1985; Thompson & Kyle, 2000; Wright, 1997). Early work by Perrin and Shapiro (Perrin & Shapiro, 1985), utilising health locus of control measures with a group of children and adolescents with chronic illness, established that locus of control varies with age and illness experience. It was also found that, with increasing age, the children in the study had a more internalised health locus of control (Perrin & Shapiro, 1985).

The question for nurses and their interdisciplinary team colleagues is whether it is possible to facilitate a sense of control over the predicament of illness and to improve efforts toward adaptation to living with illness? More recent research has examined factors associated with the trait of locus of control and adaptation to living with illness amongst 55 children aged 5-16 years (Brown et al., 2000). It was found that greater internal health locus of control was related to increasing age and was also strongly correlated with better coping and adaptation to the demands of illness (Brown et al., 2000). In another study of 112 adolescents with diabetes, which explored coping strategies used to manage chronic illness stresses, it was found that locus of control and a sense of optimism were significant predictors for coping and psychosocial adaptation to illness (Wright, 1997). Wright found that the outcome of more external locus of control varied with gender. Boys were found to have poorer treatment adherence and metabolic control whereas girls were at greater risk for poorer psychosocial outcomes.

Conversely, in another recent study, the researchers examined the way in which coping styles and locus of control influenced prediction of psychosocial adaptation to chronic illness with 84 adolescents aged 13-16 years and found no strong correlation (Meijer et al., 2002). The study showed that coping styles were more important measures of coping than locus of control, with specific coping styles being better predictors of psychosocial adaptation. Adolescents with a more problem-focused style were found to have better adaptation to illness whereas those with a more emotion focused style had a poorer adaptation (Meijer et al., 2002).

Considering the previous evidence suggesting the pervasive effect of locus of control on coping and adaptation, these results are surprising. However, it could be argued that the instruments chosen for this research may be less sensitive to measuring health locus of control and more sensitive to the other variables measured in the study (Meijer et al., 2002). Health locus of control may also vary at particular times of heightened stress as well as the duration of illness, factors which were not controlled for in the study. Health locus of control, specifically internal health locus of control, may be influential as a constituent of coping and thereby psychosocial adaptation to chronic illness. However more research, including other disciplines, is required to better understand the moderating effect of health locus of control on coping at different ages and developmental stages.

5. The utility of social and familial support

Another important moderator of stress that is also important in the process of coping is the presence of social support, or at least the perceived presence of social support (Tak & McCubbin, 2002). Social support has been well studied in the literature. There is good evidence of inverse relationships between uncertainty and social support as well as psychological distress and social support (Neville, 1998; Tak & McCubbin, 2002; Trask et al., 2003). Despite this evidence, a clear definition of social support is difficult to establish as the concept is used in the literature in a variety of ways. Social support is most commonly defined as resources that support positive emotions, physical and material needs for good health, and the provision of adequate information (Keeling, Price, Jones, & Garding, 1996). Social support in the context of chronic illness is thought to reduce the uncertainty of the situation by modifying ambiguity around the illness and treatment (Neville, 1998).

There is greater understanding of the role of social support in the coping process among the adult chronic illness literature. Spitzer et al. (1995), in a study of 77 rheumatoid arthritis patients of varying ages, further confirmed the moderating effect of social support on coping and adaptation. However, this moderating effect was mediated by a perception by the patients in the study that they felt a sense of control over their disease (Spitzer, Bar-Tal, & Golander, 1995). Social support in this study was considered to include touching, the experience of feeling cared for and the perception by the patients that they had adequate information about their disease. Better coping and adaptation to illness was achieved in this study by the presence of social support measured across a number of emotional and social factors (Spitzer et al., 1995).

Social support for children with chronic illness is probably less understood and less likely to be assessed in clinical practice. A study of 62 school-aged children with and without chronic illness showed that the children utilised social support as a coping strategy in stressful situations (Ellerton, Stewart, Ritchie, & Hirth, 1996). The healthy children had more extensive social networks compared to the children with chronic illness. The sick children reported much higher levels of stress and had more support seeking behaviours than the well children in the study (Ellerton et al., 1996). Another study of 60 adolescents aged between 14 and 22 years recently diagnosed with cancer demonstrated the moderating effect of social support on psychosocial distress (Neville, 1998). The young people in this study also experienced less uncertainty in terms of their future in the presence of perceived social support. The role of social support for children with chronic illness needs further research.

Families Coping with Chronically Ill Members

The presence of social support for families caring for children and adolescents with chronic illness is also vital to coping. The perception for the chronically ill child, that the family has social support, is particularly important (Keeling et al., 1996). Support for families includes the provision of information about the disease and ensuring that the child's family perceives a sense of control over healthcare. The involvement of families in decision-making about healthcare for their child is most important (Coyne, 1995). A study of 92 families with children under the age of 12 years with chronic illness demonstrated that perceived social support was a strong predictor of family coping and highly influential in the resilience of high-risk families (Tak & McCubbin, 2002). The presence of family support, as another dimension of social support, is a powerful predictor of good coping abilities for young people with cancer and other chronic illness (Trask et al., 2003).

A wealth of research has highlighted the important role social support for an individual with chronic illness; however, what remains less understood is what sort of social support is helpful at different psychosocial development levels. A literature review exploring 10 years of research highlighted the poor use of developmental understandings about social support and its role in the coping process (Stewart, 2003). There are links between the developmental mastery of social skills and social competency and the development of support seeking behaviours (Ellerton et al., 1996). Nursing interventions need to focus on facilitating social support for children at different developmental levels to ensure this vital personal resource is available to the process of coping.

Familial Support

The family is strongly recognised as the most important source of support enabling coping in children and young people with chronic illness (Coyne, 1997; Hentinen & Kyngas, 1998; Knafl & Gilliss, 2002; Vigneux, 1998). It is known and well supported that the presence of family support is a strong predictor of positive coping in children with chronic illness and further that good social support is integral to family coping (Coyne, 1997; Graetz, Shute, & Sawyer, 2000; Knafl & Deatrick, 1986; Kyngas et al., 2001; Patterson et al., 1997; van Buiren, Haberle, Mathes, & Schwartz, 1998; Vigneux, 1998).

The stressors and subsequent adjustments to coping with chronic illness are multiple and ongoing for children and their parents as well as the family as a unit. Specific stress points include: the point of diagnosis; specific developmental challenges such as adolescence; the realisation of dependence on healthcare services; exacerbations of the illness and hospital admissions (Melynk, Feinstein, Moldenhouer, & Small, 2001). Melynk believes there is a clear link between understanding and meeting the needs of parents and improvements to coping and thereby better psychosocial health outcomes for children (Melynk et al., 2001). Frameworks for nursing interventions to support parents become another important element in psychosocial nursing practice.

Particular sources of distress for parents are the emotional impact on them of the effect of the illness on their child, concerns about how their family will cope with current levels of distress and anticipated fears and anxieties in the future (Wochna, 1997). Family nursing care will need to understand these issues as they relate to and respond to the emotional needs of families affected by chronic illness. A recent literature review explored how parents of children with newly diagnosed diabetes experience and cope with managing the illness. The review indicated a level of insensitivity by nurses to the chronic level of grief and loss experienced by parents with chronically ill children and adolescents (Lowes, 2000). The connection and support provided by nurses caring for families is central to family coping and adaptation to having a child with a chronic illness (Coyne, 1997; Vigneux, 1998). Perhaps nurses do not recognise the value of their role in the psychosocial health outcome of the family as a group, but rather consider the outcome for the child alone as a separate in patient care.

Parents of children with chronic illness are significantly more vulnerable to mental health problems in their struggles to cope (Baine, Rosenbaum, & King, 1995; Clawson, 1996). A study exploring child and carer's ratings of adjustment to chronic illness showed that poorer family cohesiveness and increased discord were possible underlying mechanisms for depressive symptoms in the ill child (Brown & Lambert, 1999). Other researchers have identified those families who make more positive transitions to coping with illness benefit from family resilience (Chernoff, List, DeVet, & Ireys, 2001). The efficacy of interventions that target improvements in coping for families, rather than concentrating on individual children, is well supported in the literature (Drummond, Kysela, McDonald, & Query, 2002; Harkins, 1991; Knafl & Gilliss, 2002; Melynk, 2000; Vigneux, 1998; Wochna, 1997). Improvements to coping skills occur for the family as well as for individual children. The context of these studies is the paediatric context of care and outpatient settings; there are few frameworks to inform nursing practice in the adult context of care.

Parents often seek supportive responses from nurses to help them cope with their child's illness, particularly in the nurse's response to a current crisis such as emergence of a postoperative chest infection. The parents seek the nurse's response to the severity of the setback in recovery and the nurse's perception of the ability of the parents to cope. The responsiveness of nurses may well be more about personality disposition of the individual nurse than a planned and learned approach by nurse educators and mentors toward providing nursing support. A qualitative study exploring the relationships between 15 mothers of chronically ill children, nursing and medical staff found that many of the mothers described their efforts to persistently seek trusting relationships with the health staff as a constant source of stress (Swallow & Jacoby, 2001). This situation was particularly common during the pre-diagnostic stage of illness and the later chronic phase of the illness trajectory. Many of the mothers in the study often felt unheard until they developed ways to communicate with staff. Once this communication was established the mothers felt they could advocate for their child's needs no matter how difficult situations became (Swallow & Jacoby, 2001).

Family support is possibly one of the most overused phrases in the chronic illness literature and the clinical world of nursing; although there is no doubt that a shared meaning or mantra across nursing exists. Clearly it is important to support families as they experience the stressful situations in the course of healthcare. However, it is not clear what the components of this support are and whether the concept remains helpful to families in the context of changing healthcare environments. This is not to undervalue the role of nursing support for families, but a suggestion that nursing may need to update its understanding of the concept and its efficacy in contemporary chronic illness care.

Another key feature to understanding nursing support is the variability of need at different points during the illness experience. The timing of supportive interventions during the trajectory of chronic illness was the focus of a study of the parents of 189 chronically ill children (Hentinen & Kyngas, 1998). The researchers explored parental coping and adaptation and the timeliness of supportive nursing interventions using a questionnaire technique. Their aim was to better understand what factors related to support enhanced or impaired coping efforts. Nursing interventions that provided emotional support were found to be associated with better coping. The need for information about illness care was less strongly associated with positive coping and adaptation. The findings further indicated that families required more support when the child was less than nine years old than in families where the child was over nine years (Hentinen & Kyngas, 1998). There is evidence from other studies to support the notion that nursing care that offers high levels of illness related information to families is more strongly associated with better coping and adaptation among children and adolescents with chronic illness (Kyngas & Rissanen, 2001; Spitzer et al., 1995). However, other studies emphasise the importance of emotional support as having a much higher priority in nursing interventions for parents and families coping with illness (Hodgkinson & Lester, 2002; Stewart, 2003; Trask et al., 2003). The emerging nursing knowledge around the efficacy of emotional intelligence within nursing and its role in patient care is exciting and will contribute a great deal to the discourse about the value of nursing support (McQueen, 2004; Vitello-Cicciu, 2002). Nonetheless, there remains a great deal to understand about the role of emotional intelligence in patient care, particularly in supporting families in order to improve coping and adaptation to chronic illness.

The Mother-Child-Nurse Dynamic and Young People Coping With Chronic Illness

There is some discussion in the literature that the mother-child relationship and the development of coping skills is another dynamic to understand regarding the development of coping skills in young people. The coping and adaptation strengths of children and young people with chronic illness may be related to maternal coping. However, this area is not well understood or may not be addressed sufficiently in nursing supportive interventions. Hodgkinson and Lester (2002), in a recent study of current stresses and coping strategies used by 17 mothers of children with cystic fibrosis, attempted to understand more about the role of nursing practice in supporting maternal coping. They found the mothers most commonly turned to nurses for support and when seeking information about their child's care. Some of the mothers described a situation the researchers termed 'role reversal' where the mothers found they had to educate, inform and work hard to sustain useful relationships with nurses across multiple shifts and contexts of care (Hodgkinson & Lester, 2002). The researchers suggested that nursing professionals in primary and secondary care should look beyond the needs of the child to the mother. Further, they recommended nurses need to understand more about the mediating role of nursing to build hope, to connect others nurses to the care of each child and to provide continuity of care in order to strengthen relationships with parents (Hodgkinson & Lester, 2002).

The psychosocial health of mothers caring for their chronically ill children and how they participate in health care are aspects of nursing practice that are often not addressed on an individual needs level or may be missed in health care. A recent study of maternal coping explored depression and low mood amongst 324 mothers of children with epilepsy across three teaching hospitals in China (Mu, Wong, Chang, & Kwan, 2001). The mothers completed three questionnaires exploring the reasons behind their depression and low mood. The study showed boundary ambiguity, between the mothers caring for their children and the role of nurses, was positively associated with depression and low mood among many of the mothers. The study findings gave strong evidence for nursing to develop interventions that provide clear information about the role of mothers and nurses in health care. The study also provides an impetus to improve parent-child-nurse interactions that maintain family integrity and a functional role for mothers in the care of the children (Mu et al., 2001).

6. The strategy of normalising illness

Families frequently try to maintain family integrity and a sense of normality and a routine in family life. Despite the trauma and stress of living with chronic illness, many families attempt to reframe their world to live as normally as possible. In their seminal work, Knafl and Deatrick (1986) defined the act of reframing a stressful predicament, such as illness, as normalisation. The cognitive process of normalisation follows an acknowledgement by the family, or the individual, that abnormal aspects of family life associated with illness are difficult but can be reframed into a routine part of family life. The social significance of deviance from social norms, such as a child with an illness or disability, is deliberately repressed (Knafl & Deatrick, 1986).

Normalisation has four identifying criteria:

1. To acknowledge the existence of the impairment
2. To define family life as essentially normal despite impairment of a family member
3. To define the social consequences of the family's situation as minimal
4. To engage in behaviours that are designed to demonstrate the essential normalcy of the family to others without an impaired family member.

(Knafl & Deatrick, 1986)

The construct of normalisation, as described above, has been well accepted by nursing. Developing normalisation is frequently used to improve family coping, which in turn supports the child's capacity to cope with illness. Normalisation currently underpins a nursing clinical standard in some healthcare settings (Meleski, 2002). The clinical standard is used to assess the effectiveness of families to normalise illness into family life. Firstly, the family begins to manage the impact of the child's illness on family life and, secondly, to integrate the illness treatment by making adjustments to family routine (Meleski, 2002). Meleski acknowledges that the process of normalisation reflects a constant struggle with reframing and re-configuring family life to manage the fluctuations in the illness and levels of impairment. Later work by Knafl et al. (1996) refined previous work to acknowledge that the process of normalisation is not stable but evolves and fluctuates depending on family and illness situations. The refined concept of normlisation now includes five identifying criteria:

1. The family acknowledges the impairment and its potential threat to family lifestyle
2. The family adopts a normalcy lens to view the affected child and the family;
3. The parents engage in parenting behaviours and family routines with a normalcy lens
4. The family develops a treatment regimen that fits with the family's usual routine
5. Interaction with others is based on a view of the child and family as normal.

(Deatrick, Knafl, & Murphy-Moore, 1999)

The concept of normalisation is further defined as a cognitive and a behavioural process (Deatrick et al., 1999). This process is defined in the literature as a normalisation strategy (Gantt, 2002; Knafl et al., 1996; Rehm & Franck, 2000). Qualitative research exploring normalisation strategies utilised by eight families affected by HIV/AIDS disease demonstrated that the families had specific goals: the health maintenance of family members, ensuring effective school participation and the enhancement of emotional wellbeing of all family members (Rehm & Franck, 2000).

For some families it may be that the predicament of illness and the ramifications for family life are too difficult and disabling. This situation may be more difficult for nurses to accept. Knafl and Deatrick, in more recent work, have identified that some families do not view normalisation as an attainable goal (Knafl & Deatrick, 2002). Some families have sociocultural backgrounds that do not support or value normalisation. In a qualitative research study, Gantt (2002) explored the coping and normalisation strategies used by 11 mothers and their daughters with chronic heart disease (Gantt, 2002). Gannt (2002) identified predicaments or illness situations, and the impact on personal lives that could not be normalised. Factors, such as age, severity of illness and developmental state, were found to be mediators of the potential to normalise the illness. Little research has explored how to help these families when the distress is too much to bear. There is a need to identify what elements of nursing practice can help buffer and not increase their distress until their predicaments become more manageable. The process or ability of families to utilise the coping strategy of normalisation may take time. The ability may be enhanced by the experience of illness. Nurses can develop strategies to assist families to normalise their child's illness into their day-to-day lives or simply be there on an emotional level when the distress is too hard to bear. This approach to nursing supportive interventions will promote better coping for the individual with chronic illness (Meleski, 2002).

Families are vital to the process of coping for young people with chronic illness. Social support and normalisation support the efforts of individuals and families to cope with the adversity of illness. Individuals who perceive they are well supported and have the commitment of family and friends to their wellbeing react differently in crisis and suffering than those without this type of support (Slaby & Glicksman, 1985). Anxiety, depression and the sense of alienation are reduced by the presence of significant others who understand and care about the person suffering (Slaby & Glicksman, 1985).

7. The role of hope in adversity

Hope is another important component of the coping process for families and young people. The role of hope is a difficult concept to explain and is rarely utilised as a concept in nursing interventions but may be implied in nursing dialogue with patients. The sense that one is connected to other caring people seems to makes hope possible (Forbes, 1999). Hope is commonly referred to as a coping strategy when individuals are faced with threats to the safety and security of their lives (Farran, Herth, & Popovich, 1995; Forbes, 1999; Grahn, 1993; Hinds, 1988). The concept of hope is described as a way of feeling, thinking or behaving, when a crisis is looming and when more positive alternatives to undesirable events are imagined (Farran et al., 1995). Hope allows people to manage predicaments where their needs and dreams are not met or a positive outcome is considered unlikely (Hinds, 1988). Research establishing a causal model of hope in chronically ill adults emphasised that hope acts with other antecedent variables in the process of integrating chronic illness into day-to-day life (Forbes, 1999). The maintenance of hope relies on an individual's sense of meaning in life, which is diminished by the threat of illness (Forbes, 1999).

The development of hope as a constituent of coping can lead a distressed person to feel more positive, with their thoughts and behaviours becoming more adaptive to living with illness. The absence of hope can lead to maladaptive psychosocial functioning, a sense of hopelessness and despair (Farran et al., 1995). Hope is not a permanent state but variable depending on what is occurring in the person's internal and external worlds (Farran et al., 1995). Given the varying nature of hope, it may well be amenable to nursing interventions (Forbes, 1999; Rustoen, 1998). Forbes (1999) asserts that there is a wealth of research acknowledging that hope sustains people when facing crises, but there is little research into how hope can be mobilised and maintained.

Conclusion

The complexity of how individuals and families manage to cope with the stressors associated with chronic illness is clear. However, with the numbers of children and adolescents surviving chronic illnesses such as cancer, cystic fibrosis and organ transplant, this work will increasingly become a priority for health care. There is good evidence in the literature that better coping skills, among the chronically ill, are a strong predictor of better outcomes across psychosocial domains (Brooks, 2003; Fournet, Wilson, & Wallander, 1998; Meijer et al., 2002; Stewart, 2003; Trask et al., 2003). However, much of the broader research literature refers to adult coping models. Specifically, those associated with illnesses that have a greater history of survival, such as muscular skeletal and nervous disorder (Dewar & Lee, 2000; Hornsten et al., 2002; Stewart-Brown & Layte, 1997). The rehabilitative and coping strategies for chronically ill adults historically have focused on living skills, self-care, and mobility. Adolescents have these same goals but include higher ambitions such as careers, relationships and a satisfying adolescent lifestyle. I argue that if adolescents are to achieve these higher ambitions, during the course of their illness survival, better coping with their illness will optimise their opportunities for success.

The work of future research will need to focus on the assessment of coping skills and specific interventions to optimise coping skill development at different psychosocial development stages. Further, a greater understanding of particular and specific stress points along the illness trajectory and 'windows of opportunity' would facilitate coping skill development. This sort of research can assist the early identification of young people with fewer coping resources and improve the specificity of nursing and interdisciplinary interventions to facilitate the components of coping identified in this chapter.

In this chapter, I have analysed the theoretical understandings of coping skill development and identified seven components of coping that most likely interrelate in some way to engage the process of coping with chronic illness. The seven components have been brought together in this work and include the following:

1. Psychosocial developmental mastery

2. A sense of coherence
3. The trait of resilience
4. Locus of control
5. The utility of social and familial support
6. The strategy of normalising illness
7. The role of hope in adversity

These seven components will require further research and testing to establish a conceptual model. Further, exploration will determine whether these components of the coping process are personal traits or resources. Longitudinal studies of young people may inform whether better coping with chronic illness may be protective against adult psychopathology. This work will help inform clinically relevant nursing and interdisciplinary interventions that can contribute to better coping and adjustment to living with chronic illness for young people.

This chapter has expanded nursing scholarship about how young people can better cope with chronic illness to better inform policy and frameworks for nursing practice. Throughout this chapter I have argued that seven components enable coping skill development optimising the ability of young people with chronic illness to cope and adapt to chronic illness. On the basis of these findings I further argue that psychosocial developmental mastery in particular, is integral to the development of better coping skills. Given this position I decided to undertake a thorough analysis of the psychosocial development of young people with chronic illness and the role of nursing practice in developmental outcomes for this group.

In the following chapter, I will present an analysis of psychosocial development of young people illustrating the impact of chronic illness and the interplay of nursing practice, across six development stages from infancy to young adulthood. The psychosocial development of young people with chronic illness, particularly those cared for in adult hospitals, is rarely explored in the literature, and very little is known about the impact or responsiveness of nursing practice on psychosocial outcomes.

Chapter 8

The Microsystem Level of Ecological Systems Theory:
Coping with chronic illness: A developmental perspective

Introduction

This chapter is an analysis of the psychosocial development of young people with chronic illness, specifically of the impact of chronic illness on developmental mastery and of the influence of nursing practice on outcomes. The microsystem level of ecological systems theory (EST) contains the individual and the contexts within which they live including family members, peers, and other close significant family associations such as a parish priest or schoolteacher.

In my conceptualisation of EST as the healthcare world of the chronically ill young person, the microsystem theoretical explanation, or theoretical lens, is extended to include the internal world of the young person with chronic illness, the hospital environment as a temporary home, the young person's family, the nurses caring for them and the impact of nursing practice on psychosocial developmental outcomes (see orange section in diagram 7 below).

The Microsystem

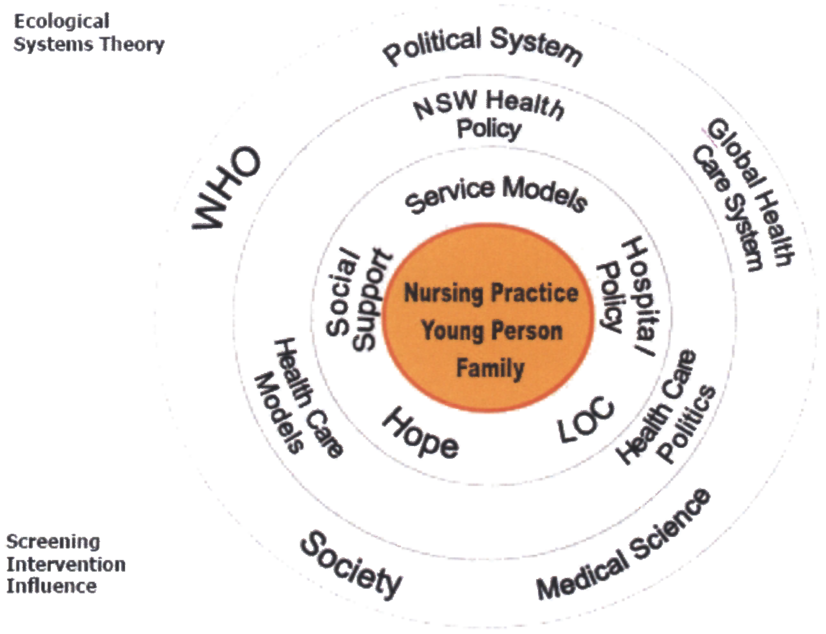

Diagram 7

I have selected literature for this discussion that specifically relates to the developmental stages of psychosocial development and the interplay of nursing practice.

As discussed previously in Chapter 4, the psychosocial development of adolescence occurs across a lifespan of arguably 20 - 24 years. At this stage, the young person closes the developmental period of adolescence, by entering the stage of young adulthood. The level of detail in Bronfenbrenner's ecological systems theory, particularly at the microsystem level, does not allow for a lifespan analysis. What I required was a set of explanations of developmental progress at each stage in order to analyse the role, or potential role, of nursing practice frameworks to optimise psychosocial outcomes for the group. I use Erikson's theory of psychosocial development to extend the analysis of the microsystem to include a stage-by-stage discussion of psychosocial development occurring within the internal world of young people with chronic illness and the interaction with nursing practice.

The analysis draws on case studies highlighting everyday challenges in chronic illness nursing practice to identify risks, and points to several ways in which the clinical care of young people may facilitate and optimise psychosocial developmental mastery. In Chapter 7, I have argued that among other factors, psychosocial developmental mastery sits at the heart of coping skill development and adaptation to illness. Nursing practice has considerable agency within the microsystem level of EST, represented by the day-to-day healthcare world of young people with chronic illness in an adult hospital, to implement or augment existing healthcare interventions to optimise opportunities for psychosocial development. However, there has been a considerable gap in knowledge about the internal world of young people with chronic illness and the role of nursing practice in optimising outcomes. In regard to nursing practice, it is not clear what impact nursing practice has on psychosocial development or what frameworks may inform interventions that are more responsive.

The Microsystem and the Inclusion of Erikson's Theory of Psychosocial Development

The defining principles of the microsystem were discussed in Chapter 4. Briefly, to set the scene for this chapter, Bronfenbrenner defines the microsystem as containing patterns of activities, roles, and interpersonal relationships experienced by the developing person in a given setting. 'This setting has particular physical and material features, containing other persons with distinctive characteristics of temperament, personality, and systems of belief that influence the development of the person' (Bronfenbrenner, 1989, p. 226). The environmental attributes of the microsystem are analogous to the environmental features, physical and social, required for good psychosocial development. These features or environmental developmental influences include a sense of physical comfort and trust in the environment, in particular the positive temperament and systems of belief among caregivers (Erikson, 1968).

Within the analysis of the microsystem, I include Erikson's theory of psychosocial development and, to a lesser extent, other child development theorists. Whilst the focus of this thesis has been on adolescents with chronic illness, the discussion in this chapter includes the psychosocial developmental stages from infancy through to young adulthood. There are two reasons for this extensive discussion. Firstly, Erikson argues that developmental milestone failure is cumulative in its effect at each individual psychosocial stage on adult psychosocial health outcome. Secondly, critical points in the development of factors that come together to enable coping, discussed in Chapter 7, largely occur during the psychosocial developmental experiences of childhood and adolescence. There is some evidence in the literature that generally psychosocial developmental task mastery is important in the development of good coping skills (Hornsten et al., 2002; Livneh et al., 2004; Madden et al., 2002). However, there is little discussion or evidence in the literature about why each stage is important or about the role of nursing practice in influencing developmental experiences which facilitate mastery and thus coping skills. Given this situation, the six stages of psychosocial development from infancy to young adulthood (Erikson, 1968) are discussed in this in order chapter to examine the impact of chronic illness on psychosocial development and analyse the role for nursing practice. Case studies are utilised to illustrate the impact of chronic illness on the psychosocial development of children and adolescents with chronic illness and the role of nursing practice (the names of the children and young people have been changed to maintain confidentiality).

The Psychosocial Development of Young People with Chronic Illness

The opportunities for developmental experiences that promote healthy psychosocial development may be limited or compromised by illness, and possibly by nursing practice. The presence of chronic illness may disrupt the pace and timing or, indeed, may regress developmental milestone achievement. Long absences from school and limited opportunities for self-responsibility or the experience of achievement, can both compromise developmental mastery. The feelings of difference from peers and the experience of an inconsistent peer group make it even more difficult for some young people to achieve developmental milestones.

The sequencing and progression of psychosocial development is shaped by day-to-day life experiences and interactions within families and other people in the community (Erikson, 1968). Children and young people with chronic illness often have long hospital admissions isolated from family members and peer groups. Times of life threatening crises, persisting anxiety and distress, endurance of pain and long hospitalisations can limit developmental experiences for psychosocial task experimentation and mastery. Further challenges emerge when the physical effects of the disease and treatments, such as short stature, weight gain or loss, disabilities, jaundiced skin colour and (for some) hair loss increase the sense of difference from well peers (Gurney et al., 2003). There are numerous environmental mediators that can act as, or become, protective factors, when an individual is faced with developmental compromise. These environmental factors can also be risk factors for developmental compromise and risk adult psychopathology (Burnet & Robinson, 2000; Stuber, 1996). Other factors, such as the severity and visibility of the illness, current health state, duration of the illness and time since diagnosis, can also impact on the developmental environment to predispose or protect the young person from the adverse effects of illness on psychosocial development (Brown et al., 2000; Pollock & Sands, 1997; Stuber, 1996; Wolman et al., 1994). However, the relationship between these factors and how to moderate the environment is complex and rarely examined (Vessey, 1999).

I now begin the discussion exploring Erikson's theory of psychosocial development at each stage from infancy through to young adulthood, the impact of chronic illness and responsiveness of nursing practice. The six psychosocial developmental stages include:

1. Trust versus mistrust – Infancy (first year of life)
2. Autonomy versus shame and doubt – Infancy (second year of life)
3. Initiative versus guilt – Early childhood the preschool years (3-5 years)
4. Industry versus inferiority – Middle and late childhood (infants and primary school – 6 years through to puberty)
5. Identity versus identity confusion – Adolescence (10 – 20 years)

6. Intimacy versus isolation – Early adulthood (20s and 30s).

(Erikson, 1968)

1. Trust Versus Mistrust – Infancy (first year of life) and the sick infant

Erikson's first psychosocial developmental stage, from birth to one year of age, begins with the conflict of basic trust versus mistrust. This conflict is resolved if the infant experiences a sense of trust about having his/her needs met without high levels of anxiety or distress. For example, the situation of distress may arise for infants while waiting for care in busy hospital wards or with inconsistent caregiving or in the absence of parental care. Delays in the gratification of the infant's needs and persisting anxiety can induce a poor or negative resolution of the conflict of trust versus mistrust. A negative resolution of this stage can result in feelings of mistrust and anxiety about the responsiveness of the environment to meet the infant's needs in the future (Erikson, 1968).

The resolution of this first developmental stage is also important to the process of attachment to a caregiver in infancy. Bowlby, a major attachment theorist, believed that it is in fact the infant that elicits care by a series of built-in behaviours such as crying, sucking, clinging, gazing and smiling rather than the parent initiating caregiving (Bowlby, 1969). The caregiver, however, needs to be sensitive to these cues from the infant in order to respond appropriately to their needs. In the case of a sick infant, distance from the primary caregiver can result in separation anxiety and an anxious attachment (Bowlby, 1969). This situation may compromise the development of trust inherent in Erikson's stage of trust versus mistrust. The post-natal stage of development is a 'sensitive period' when bonding can occur and attachment to a consistent caregiver, ideally a parent, can begin (Henze, 1995). Clearly, illness and hospitalisation during early infancy can put at risk the quality of attachment and the development task to accommodate a sense of trust in the environment for sick infants.

Bower (1992) challenged the idea that a consistent caregiver was necessary for an infant to form a secure attachment. Using an ethnographic study design, Bower observed the social lives of 23 children of the Efe tribes in Africa. The study focused on the caregiving received by the children from infancy to three years of age. The children were cared for by a range of adults and breast fed by many different women from the tribe. Older children were observed to constantly carry the infants in the study. The infants were rarely alone and never out of sight of caregivers (Bower, 1992). The children maintained close emotional ties with, and a sense of attachment to, many caregivers. The premise of both Erikson and Bowlby's theories about the importance of trust in the environment and the development of secure attachments remain convincing in the context of the Bower study. The important point here is that the conflict of trust versus mistrust can be resolved when the infant develops a sense of trust that their needs will be met but not necessarily by a parent, as demonstrated by the Bower study.

The cohort in Bower's study sample is analogous to the situation in a hospital ward or neonatal unit with its multiple caregivers. The decisive element for the resolution of this conflict of trust versus mistrust and a positive psychosocial developmental outcome for stage is the experience for infants of timely, responsive and consistent nursing and/or parental care, rather than one-person continuity of care.

A more recent Israeli quantitative and qualitative study of 758 infants explored the unique contribution of various forms of caregiving to infant attachment (Sagi, Koren-Karie, Motti, & Joels, 2002). The study compared care provided to the infants by their mothers, care by relative and paid caregivers in a family day care facility. Many of the infants were found to have poor quality attachments with caregivers across all groups. This was particularly noticeable in the day care setting. The researchers considered that it is most likely poor quality care, inconsistencies in the responsiveness of care and a high infant caregiver ratio that accounted for the increased levels of attachment insecurity found in the study (Sagi et al., 2002). This study does provide support that, for an infant to resolve the conflict of trust versus mistrust, psychosocial developmental experiences are needed which ensure that the infant trusts that his/her needs will be met in a timely, responsive, and consistent manner. Given the findings of this study, it is reasonable to assume that the experience for an infant of inconsistent and poor quality care in a hospital ward, particularly in the instance of high infant caregiver ratios, may contribute to a poor resolution of this stage for developing infants. An awareness of this situation can provide an opportunity to improve the experience of sick infants in hospital wards.

Diseases associated with prematurity, a low birth weight and congenital abnormalities often result in prolonged hospital admissions compromising infant bonding and attachment behaviours (McGrath, 2001). In an American study of a neonatal intensive care unit, Miles (1999) explored whether teaching mothers to elicit cues from their premature infants could guide responsive care giving. It was found that the mothers who were taught how to respond to their infant's cues, such as crying, smiling and gazing, were able to bond quicker and were more able to care for the infant, despite the high level medical care (Miles, 1999).

The separation of sick infants from their mothers, and the infant's experience of high levels of stress, has been found to negatively impact on the early development of emotional self-regulation and attachment to the mother. In a study of 100 mothers and their seven-month-old infants, the relationship was explored between maternal facial representations and the resultant effect on infants, by observing infant facial expressions (Rosenblum, McDonaugh, Muzik, Miller, & Sameroff, 2002). The study demonstrated that mothers, who had balanced facial expressions while looking at their infants, rather than constant, still facial expressions, could elicit positive emotions from their infants. The researchers believed the role of maternal affect, represented by facial expressions to infants, can influence early emotional development in infants and the initiation or presence of balanced expressions can repair temporary disruptions in interactions (Rosenblum et al., 2002). The findings highlight the need to monitor maternal affect and emotional state in infant health care as well as how to support positive emotional development in infants.

Other researchers have reported that teaching parents positive touch skills for sick infants and rooming-in promote secure attachments and a higher incidence of breast feeding at three months into the post-natal period (Bond, 1999; Leavitt, 1999; Norr, Roberts, & Freese, 1989). Sensitive, responsive caregiving is a powerful predictor of secure attachment (Bowlby, 1969). It seems likely that constancy, rather than the continuity of the same person in the caregiving role, can optimise resolution of Erikson's first stage of trust versus mistrust for sick infants. Clearly, the infant and the environment are interactive systems that have potential moderators to facilitate or impede psychosocial development. This interaction and outcome occurs despite the presence of illness, medical care, and hospitalisation. The important components are most likely quality, timely, and responsive care. However, classic research, such as the Bower study, holds that the important fact is that as long as the same caregiver provides responsive care or a range of caregivers the outcome for infant will be positive (Bower, 1992). Nonetheless, parental attachment, albeit a Western prerogative, is still the ideal developmental outcome, but it may not be critical to resolving Erikson's notion of trust versus mistrust.

2. Autonomy Versus Shame and Doubt – (second year of life) and the sick toddler

Erikson's second stage of psychosocial development, from the age of one to three years, involves resolving the conflict of autonomy versus shame and doubt (Erikson, 1968). The child discovering a will of its own marks this stage. The child begins to walk, climb, and develop the mental powers of making decisions. Autonomy begins to form during this stage when parents or caregivers offer guided choices and do not overly restrict, force or shame the child (Erikson, 1968). Children restrained too much or punished too harshly can risk the development of a sense of shame and self-doubt during this stage (Erikson, 1968). For young children with chronic illness the achievement of walking and climbing may be impossible or delayed by the impact of the disease process. Incapacity and physical limitations may also compromise the attainment of a sense of competence for children with chronic illness. A negative outcome for children during this stage may result in the child developing feelings of shame and self-doubt about competence.

The diagnosis and treatment of chronic conditions often involves multiple painful and traumatic procedures that may embarrass and shame young children. The hospital experience can become an extremely stressful period for both the child and the family. The anxiety that may be experienced during invasive and traumatic procedures can have psychological effects that linger for months after discharge from the hospital (Melynk, 2000). It is important to consider the developmental impact of stressful and traumatic experiences for young children in hospital. However, for young children this cannot be considered in isolation to family considerations in regards to the developmental impact of healthcare.

The Role of Parents in Resolving the Conflict of Competency Versus Shame and Doubt

Parents are frequently forced to relinquish control over their child's care when the child is hospitalised and thereby their ability to protect their child from harm (Balling & McCubbin, 2001; Bricher, 2002). As long ago as 1953, seminal work unpacking the distress of illness and hospitalisation for children and parents stated that nurses and doctors develop a protective blind spot about the rights of parents and children as they endure the traumas of illness treatments (Robertson, 1952). This situation seemingly reduces the sensitivity of health staff to the often-silent distress experienced by hospitalised children and families undergoing medical procedures. Much later, in 1996, Thomas believed much remained to be achieved in reducing the psychological trauma experienced by children in healthcare facilities, despite a resolution on a convention for the Rights of the Child in 1989 (United Nations, 1989). It seems that more debate is necessary within health services and with families on how to truly give a voice to the rights of children and families in health care and how to reduce the distress of the illness experience and the hospital experience generally.

The experience of being in hospital and the psychological experience of healthcare interventions need a great deal more consideration. We need to consider the meaning and impact of the healthcare experience, not only for children but also for families/carers, created by hospital architecture and general clinical milieu as well as the way children are prepared for and recover from medical procedures. Focus groups involved in the development of a new children's hospital in Britain identified three key elements crucial in design: the child's eye view of the clinical environment; how the place feels to a child; the need for a relaxed, interesting and secure environment for the child and their family as a whole (Haines & Johnston, 2001).

Nurses, in partnership with parents, need to ensure opportunities to develop the child's sense of self and competence, enabling the resolution of the conflict of autonomy versus shame and doubt despite the context of the healthcare environment. Opportunities can be created in health care for children to make decisions, assert boundaries about the touching and handling of their bodies, thereby discouraging prolonged anxiety and minimising the feelings of shame and doubt. Given the close developmental relationship between parents and young children and the importance of emotional support for parents established in previous chapters, the parental experience should not only be a priority in health care generally, but specifically to ensure developmental progress and optimal readiness for the next resolution and milestone in development.

Illustrating Responsive Nursing Practice: Case study of 'Sophie'

I now illustrate, using the case study of 'Sophie', the potential compromise to the resolution of the conflict of autonomy versus shame and doubt inherent in hospital care. 'Sophie', aged three, affected by congenital dislocation of the hips since birth, has required frequent and long hospitalisations for treatment. The treatment to correct 'Sophie's' problems with her hips has involved traction and surgery. 'Sophie' has been unable to walk unaided and climbing is particularly dangerous for her. She can crawl but indignantly continues to try to walk when not in traction. Developmental considerations in 'Sophie's' nursing care include the effect of traction, short-term restraint for procedures, and the innate desire to walk at this age that compromise her treatment. The restraint of children for traction and diagnostic procedures are frequent activities in clinical care, but the psychological effect of restraint, short and long-term, is not fully appreciated. Clearly, a child restrained in traction 24 hours a day or restrained for procedures requires particular consideration in terms of emotional support and the provision of alternative developmental opportunities that do not risk the outcome of treatment. Erikson suggests that excessive restraint or too severe punishment can result in a sense of shame and doubt emerging from this developmental stage (Erikson, 1968). Opportunities can be created in the day-to-day nursing care for children like 'Sophie' to allow them to make decisions to experience their own self will and to participate in play.

There are methods to reduce the stressful experience of restraint used during traumatic procedures for young children and opportunities to optimise the outcome of the conflict of autonomy versus shame and doubt at this developmental stage. Techniques such as distraction, inherent in play therapy, can be used to minimise the adverse effects of restraint (Collins, 1999). A meta-analysis exploring the efficacy of play therapy, particularly for children undergoing medical procedures, found a strong relationship between treatment effectiveness and the inclusion of play into the procedure (Leblanc & Ritchie, 2001). Play therapy can reduce the anxiety of medical treatments for young children and have a significant role in maximising developmental opportunities during long hospitalisations for very young children (Mathiasen & Butterworth, 2001).

The preparation of children for the hospital and illness treatment experience in order to minimise the distress and the impact on behaviour is becoming a common component of paediatric admissions. The intention is to minimise anxiety and behavioural problems following discharge. A study by Zahr (1998) also provides support for the effectiveness of play therapy in minimising the anxiety around traumatic procedures for children and developmentally regressive behaviours after discharge. Fifty preschool children who received play therapy one day before hospital treatment were compared with a control group of children who received routine care in a Lebanese hospital. The findings indicated that play therapy reduced anxiety and statistically significantly lowered scores on a Post Hospital Behaviour Questionnaire when compared with controls (Zahr, 1998). Clearly, efforts to reduce anxiety and improve the hospital experience for young children can improve behaviour and facilitate a better psychosocial experience. This outcome can assist the resolution of the conflict of autonomy versus shame and doubt critical to this stage of psychosocial development for young children.

Despite the routine practice of restraining young children and the use of traction at this age, little is known about the psychosocial effect of such procedures. Collins (1999), in a recent review of the literature, found very few papers examining the psychosocial impact of traction and the use of restraint during clinical procedures. There was little evidence in nursing programs or the nursing literature on the issues of consent or alternatives to physical restraint for procedures. There are a few studies that have indicated that nurses, experience discomfort when they restrain children for procedures (Collins, 1999). Collins suggested that the lack of nursing research in the area of restraint may be associated with the reluctance of nursing to address the legal, ethical and psychological issues inherent in the practice (Collins, 1999).

3. Initiative Versus Guilt – Early childhood (3-5 years) and the sick preschool child

The third stage of psychosocial development, initiative versus guilt, occurs from the ages of three to five years (Erikson, 1968). This stage involves make-believe and developing imagination, where children playact roles encountering a widening social world (Erikson, 1968). Children at this stage need to have opportunities to experience initiative, ambition, and a sense of responsibility. A positive resolution of this stage can result in giving children a sense of purpose and a meaningful direction in their behaviours. The possible negative attainment of this stage is the development of a sense of guilt, particularly if the demands of parents or carers for self-control lead to over-control, compromising the attainment of initiative and fostering feelings of guilt.

The psychosexual development of young children, a key component of psychosocial developmental mastery, is also underway during this stage. Discontinuity in psychosexual development can have profound effects on ongoing psychosocial development of individuals (Erikson, 1968). Children at this stage are developing a sense of awareness about their body integrity and often develop fears about death or mutilation. Whilst in hospital children often have their bodies exposed and probed by strangers or hear from other children about their experiences. For some children this can create high levels of anxiety. Physical and emotional manifestations of anxiety are common amongst young children in hospital, such as anger, withdrawal, regression, bedwetting, and sleep disturbance. A study validating an instrument to measure anxiety levels amongst hospitalised children with chronic conditions demonstrated a strong association between more negative behaviour manifestations and high levels of anxiety (Clatworthy, Simon, & Tiedeman, 1999).

A thorough understanding of the psychosexual development of children and adolescents is crucial to minimise the negative impact of examinations and procedures. A study exploring the knowledge of 87 nurses about psychosexual development and the extent to which they incorporated this knowledge into their clinical practice in a large paediatric hospital showed that the nurses believed they generally had good overall knowledge and positive attitudes about the psychosexual needs of children (Popovich, 2000). However, on individual analysis, there was lack of agreement on whether or how to incorporate the psychosexual needs of children into nursing practice (Popovich, 2000). Many of the subjects indicated that children's sexuality is often viewed in adult terms, or in terms of protecting children from abuse, and further that many nurses had little knowledge about the psychosexual development of children. The study findings also indicated that the nurses' own attitudes about sexuality affected their ability to change practice (Popovich, 2000).

Illustrating Responsive Nursing Practice: Case study of Alice

I now utilise the case study of 'Alice' to illustrate the impact of hospital and illness treatment experience on a young child and, in particular, the impact on the resolution of the conflict initiative versus guilt. The case example of five-year-old 'Alice' admitted to hospital for the treatment of Juvenile Rheumatoid Arthritis (JRA) illustrates the vulnerabilities of children attempting to resolve the conflict of initiative versus guilt. JRA requires multiple hospital admissions, regular monitoring via blood tests and daily activities involving exposure of the child's body to strangers. 'Alice' may perceive these experiences as an intrusion or mutilation and feel she has little control or is forced to relinquish control over the behaviour of strangers and/or her own behaviour. Alice required opportunities to allow her to control the situation and she needed some help to maintain boundaries around strangers touching her body. Children may feel guilty at allowing strangers to touch and probe their bodies, particularly in the absence of parents (Erikson, 1968; Popovich, 2000). In contrast, without specific psychological preparation for the parent and the child, the child may also feel betrayed by the parent who allows the intrusion, particularly if the parent is present during the examination. A child such as 'Alice' in this situation risks a negative resolution of this developmental stage and may develop feelings of shame, guilt and persisting anxiety around sexuality (Erikson, 1968). There is opportunity, however, that with sufficient psychological preparation, a sense of autonomy and self-control could have been achieved to optimise the resolution of the conflict of initiative versus shame and doubt. This would include a protective role created for the parent to protect Alice's modesty during examinations and insist that strangers ask permission to touch her body.

Nurses are in key positions to change the culture of care, hence the developmental experience for young children in hospital during such an important stage of psychosocial and psychosexual development. Young children need assertive adults around them to advocate for them, to create opportunities for them that promote choices allowing them to make decisions about how procedures will be carried out, and particularly to include their parents. When adults respect the decisions made by children, they have the opportunity to convey to the child a sense of self worth and confidence in the child's ability to control the situation or the child via the parent. This situation also provides opportunities for the child to begin learning protective behaviours, building the understanding of adults that they must ask permission before touching children's bodies. Developmental mastery of this stage is particularly important for children with chronic illness and disabilities. Achievements for children such as having some control of their bodies and their world can optimise their opportunities to achieve the next stage of learning, cooperating with others to begin the work of self care and taking part in managing their illness.

4. Industry Versus Inferiority – Middle and late childhood (6 years through to puberty) and the sick school age child

The fourth stage of Erikson's developmental theory, attainment of industry versus inferiority, marks the period from six years through to puberty. This stage includes starting school and the capacity for productive work, cooperation with others and a sense of pride in one's work. Feelings of inferiority can develop if the child's experiences at school, with their peer group and with parents or carers do not foster feelings of competence and mastery (Erikson, 1968). Children with a chronic illness often have long absences from school and experience an inconsistent peer group (Berk, 1991). The child's illness may be significantly visible and invoke ridicule from peers or persistent and intruding curiosity from adults, potentially fostering feelings of inferiority and anxiety.

The potential for unrecognised and persistent anxiety for chronically ill children is of particular concern. Anxiety in this group is often represented by behaviour problems exhibited by children in this age group with and without chronic illness (Hersen, 2005). Persisting anxiety in children at this age leads to regressive behaviours and the loss of previously attained milestones, developmental delays, feelings of isolation from peers and loneliness (Rossen & McKeever, 1996). Among children who experience regression or developmental delays, the early recognition of behavioural change and somatic symptoms may be the key to understanding, predicting, identifying, and ameliorating their distress (Ziegler & Prior, 1994). Examples of these behaviours among hospitalised children may be a recurrence of bed-wetting and extreme separation anxiety or a persistent leg weakness unrelated to the child's diagnosis or treatment (Ziegler & Prior, 1994). Erikson considers the greatest danger for children during this stage of psychosocial development is to experience feelings of incompetence, feeling unproductive and feeling inferior to their peers (Erikson, 1968). The experience of illness and hospitalisation is clearly a risk for children at this stage of development to either regress to previous levels of mastery or not be able to adequately resolve the conflict of industry versus inferiority. This is particularly important for children with physical and intellectual disabilities.

Physical and intellectual disabilities are common among children and adolescents with chronic illness. It is critically important for these children that their level of mastery is known and opportunities for developmental progression are considered. At the very least, hospital experiences should try to minimise regression in developmental milestones, albeit that this is difficult when health care can be especially frightening to disabled children. The recognition of anxiety among children with intellectual disabilities is particularly difficult. The importance of ensuring that the hospital experience of these children minimises anxiety and provides opportunities for a sense of achievement cannot be understated.

Illustrating Responsive Nursing Practice: Case study of 'David'

This case study involves 'David' a young boy with an intellectual disability. Erikson's conflict of industry versus inferiority is a particularly important stage and milestone for many children with disabilities. I have chosen 'David's' story to analyse and highlight the importance of recognising developmental mastery among children with disabilities and the key role of nursing practice to influence the hospital experiences of this group. The case example of 'David', an 11-year-old boy with Down's syndrome, highlights not only the importance of identifying anxiety but also how difficult it is to recognise behavioural developmental cues and to ensure responsive nursing care. 'David' was admitted to hospital for further medical management of congenital heart defects that were now impairing his cardiac function. 'David', prior to admission to hospital, was able to assist with dressing and, after prompting by his mother, could almost use the toilet by himself. Early in the admission, the insertion of a cannula was required to administer antibiotics. 'David' thrashed about violently and needed to be restrained for the procedure. After the procedure, 'David' remained aggressive, incontinent, spitting and refusing to swallow medication. He eventually pulled out the cannula. 'David's' mother became visibly distressed and later disclosed feelings of powerlessness and inability to control her son's experience in the hospital. She also felt 'David' was aware of her distress and her inability to protect him.

The anxiety levels of mothers are reported to be a powerful predictor of anxiety amongst children in this age group (Small, 2002). Insight into maternal anxiety can also be a window to understand, predict, identify, and perhaps intervene with, distressed children. Understanding and ameliorating maternal anxiety may potentially be another environmental mediator to reduce the anxiety of hospitalised children and to facilitate resolution of the conflict of industry versus inferiority. At the very least, it may prevent development regression and the loss of previously acquired or current achievements. In the case of 'David', it may have been a loss of previously attained skills and current developmental mastery, such as toileting, feeding himself, feeling safe and his able to control his behaviour.

The perspectives and knowledge of parents and carers of the child's mood, behaviour, and particularly information about premorbid function are extremely valuable in understanding the child's psychosocial functioning and current state. In particular, with children such as 'David', it could be useful to explore previous developmental achievements, specifically emotion regulation, feeding, bathing or the level of support required for these activities. Young children often find it more difficult to articulate their distress in a meaningful way; this is particularly apparent for children with developmental delays. A mild sedation for 'David' and appropriate preparation for the traumatic procedures, both for 'David' and his mother, may have reduced the need for restraint and the level of anxiety that ensued. Routine monitoring of mood, emotions, and behaviour and functioning before and after traumatic procedures can identify rising anxiety for both mothers and their children. Identifying anxiety can create opportunities to ameliorate distress and avoid losses to developmental mastery.

Nursing interventions that target maternal anxiety are important in moderating the anxiety of children undergoing traumatic procedures. Small (2002), in a literature review, identified that anxious and depressed parents were highly predictive of poor coping outcomes for their children during and/or following medical procedures and hospitalisations. A recent randomised control trial was conducted to explore the effect of interventions targeting maternal anxiety and depression among 163 mothers of hospitalised children in two paediatric hospitals. The level of anxiety and depression among the group was measured at intervals of 1, 3, 6, and 12 months after hospitalisation (Melnyk et al., 2004). The study showed that the use of specific interventions to reduce maternal anxiety strongly reduced child anxiety and less negative behaviours after discharge. The researchers concluded that with routine provision of interventions that reduce maternal anxiety, negative outcomes such as developmental regression following discharge could be substantially reduced (Melnyk et al., 2004). Nursing interventions that empower the child and/or normalise the hospital experience as much as possible, particularly for children with developmental delays, may promote developmental opportunities. Interventions that consider the challenges to development progression can also promote the retention of previous levels of developmental mastery. Developmental regression can weaken opportunities to resolve and master following developmental conflicts and milestones, such as moving from childhood to adolescence, are clearly critical in optimising self-care and independence as adults.

5. Identity Versus Identity Confusion – Adolescence (10-20 years)

and the sick adolescent

Erikson (1968) marks adolescence from ages 10 until 20 years as the fifth stage of human psychosocial development. This stage presents the conflict of identity versus identity confusion and the transition from childhood to adulthood. The achievement of the earlier developmental tasks, regardless of the quality of mastery, becomes integrated into a lasting sense of identity and an emerging recognition of one's place in the society. A more negative outcome is recognised by identity confusion, sexual identity, and future occupational potential. Erikson also sees the satisfactory integration of mutuality between the mothering adult and mothered child as a vital component to identity formation during adolescence (Erikson, 1968).

Erikson acknowledges that, from a genetic point of view, the process of ego configuration evolves gradually with successive ego synthesis and resynthesis under the influence of the individual's genetic code and environmental moderators (Erikson, 1968). Environmental moderators, such as parenting, community attitudes, and cultural beliefs, remain powerful in shaping the developing ego of the adolescent (Bronfenbrenner, 1979; Erikson, 1968). These environmental moderators are responsible for the nature of developmental experiences for young people, albeit positive or negative, in the configuration of the final ego that emerges into adulthood.

The achievement of a sense of identity is a particularly critical stage for optimal independent functioning and mental health for young people with chronic illness. Young people with chronic illness may spend long periods in hospital or be confined largely to their homes. This situation limits the experience of a social context of peers and the community to work on the developmental conflict of identity versus identify confusion. Other vital experimentation with roles, normal levels of risk taking behaviours and the development of cognitive abilities has the potential to be limited compromising developmental opportunities. The compromising and cumulative effect of fewer developmental experiences and poorer psychosocial development becomes apparent when the young person reaches adolescence. Given children and young people spend so much time in hospital during infancy, childhood and adolescence nursing practice is a significant environmental moderator with the potential to create opportunities for psychosocial growth and development in day-to-day hospital experiences.

Adolescent psychosocial development is to some extent innate but it is largely mediated externally by the social context of the young person and shaped by the perceptions of others in their environment as well as by self-perception (Santrock, 1998). Other factors such as cultural beliefs, community attitudes toward youth, economic factors, and the media further mediate developmental experiences in the social environment of adolescents (Millstein, Nightingale, Petersen, Mortimer, Allyn & Hamburg, 1993). The changing nature of society and attitudes toward chronically ill young people can have compelling effects on opportunities for their identity development and their lifestyle choices for young people.

Adolescence brings significant biological, cognitive and psychological changes ranging from the development of sexual and reproductive functions, abstract thinking processes and the beginnings of independent functioning (Santrock, 1998). The physiological changes associated with puberty are generally considered to mark entry into the developmental period of adolescence. The outward sign of puberty seems to initiate the expectation by parents and the society of more adult type behaviours by adolescents. For many young people with chronic illness the biological markers of puberty are not helpful to distinguish the developmental stage of adolescence. In particular, diseases or treatments that involve the renal or endocrine systems often disrupt the normal timing and tempo of growth and development, which is particularly noticeable during adolescence (Blum, 1992; Cicognani et al., 2003; Friedman & Meadows, 2002; Gurney et al., 2003). For young people with chronic illness physical difference from peers is most apparent during adolescence. Disrupted or delayed growth and development are not as obvious or challenging to children as a comparatively short stature is often missed by other children and is perhaps more acceptable and manageable to adults. However, adolescence is normally a time of significant growth and development, and being more like one's peers becomes the most important aspect of life. A sense of rejection or an awareness of difference can mean stress, frustration, and sadness (Santrock, 1998). The constant sense of comparing one's self to others is a predominant pastime of adolescents. The well adolescent may be rapidly developing physical, psychological and psychosexually, whilst the chronically ill young person may be developing at a slower rate, heightening the sense of difference.

Erikson believes that it is not the rapid growth and sexual impulses per se that disturb adolescents, but an acute fear of being different or of not conforming to a peer group (Erikson, 1968). Clearly, for the chronically ill young person, this situation can cause a higher level of anxiety. Young people also worry about the future and how they will be able to have an independent lifestyle (Erikson, 1968). The visibility of a disease, in terms of physical difference from peers and forced dependence on others for care, presents major developmental challenges to the conflict of achieving a sense of identity. The integration of a sense of self and a feeling of confidence of one's own role in the society is clearly a major challenge for young people working through the developmental period of adolescence (Abraham, Silber, & Lyon, 1999; Cameron, 1996; Stewart, 2003). The resolution of this stage, for many young people with chronic illness, is either not possible or is delayed until they reach their twenties or thirties. More often, the developmental trajectory does not conform to the timing and tempo of Erikson's stages of psychosocial development or, more importantly, is at a different pace or not visible to others, when compared to their well peer group (Blum, 1992; Santrock, 1998).

Understanding Psychosocial Developmental Discontinuity and the Chronically Ill Adolescent

Discontinuity and poor congruence between psychosocial mastery and physiological development is common amongst the chronically ill (Blum, 1992; Daum & Collins, 1992; Hornsten et al., 2002; Kieckhefer, 2000; Santrock, 1998). For example, a young person may be developing at a normal rate for a 14-year-old psychologically, but have a body size and shape of a much younger child. In contrast, a 20-year-old might be considered to have a normal size and body shape but will express the emotions and behaviours expected of a 10-year-old highly dependent on parental care. Understanding the developmental level of a child or young person with a chronic illness is clearly complex. The most effective approach is to develop a rapport with the young person and undertake a comprehensive bio-psychosocial assessment (Blum, 1992; Gjaerum & Heyerdahl, 1998; Melynk et al., 2001). In health care, misunderstanding a young person's developmental stage can not only compromise developmental opportunities but also the therapeutic relationship, central to working effectively with young people with chronic illness. The presumption, particularly by healthcare staff, that a chronological age or outward physical appearance of adolescence can guide the expectations of appropriate behaviour, emotions and is indicative of independent functioning, can be quite damaging to relationships with these young people and their parents.

For many young people with and without chronic illness adolescence may not be a period of normative disturbance. Notions that adolescence is inherently difficult and that progression is based on the development of a coherent identity and independent functioning are challenged particularly in the presence of chronic illness. If the termination of adolescence or identity achievement were reliant on these factors, then for some young people with chronic illness it would never end (Cooper, 1999). There is evidence that the majority of young people pass through adolescence without developing significant social, emotional, or behavioural difficulties. Furthermore, for those who do have problems, they are often relatively transitory in nature and resolved by adulthood (Steinberg, 1999). This is also true for young people with chronic illness. Clearly an open-mind and astute developmental mastery skills are essential to adolescent health nursing practice.

For many young people with chronic illness adolescence is a particularly difficult developmental period (Miauton, Narring, & Michaud, 2003; Zahn-Waxler, Klimes-Dougan, & Slattery, 2000). There is some evidence that prolonged psychosocial difficulties during adolescence do risk adult psychopathology (Steinberg, 1999). A longitudinal study comparing levels of depression among adolescents indicated that experiences of excessive anxiety and distress during childhood might predispose to depressive states during adolescence, rather than as a consequence of adolescence in itself (Zahn-Waxler et al., 2000). Erikson's view, that the resolution of the crises of adolescence is directly affected by the quality of the resolution of previous stages in psychosocial development, is certainly supported by the work of this study. It is reasonable to suggest that difficult illness experiences, particularly those resulting in greater anxiety during childhood, may be a factor in why some young people struggle with their psychosocial health and functioning during adolescence, and may be at greater risk of psychopathology.

Parents and the Psychosocial Development of their Chronically Ill Adolescents

The developmental period of adolescence is also confusing and challenging for parents of young people with chronic illness. Parents of children with chronic illness often feel their child had already adjusted to having a chronic disease but once they entered adolescence they became more difficult to manage, being determined to break the rules and becoming manipulative with treatment adherence (Blum, 1992). Perhaps the earlier adjustment was more reflective of parental adjustment to the disorder and the treatment, with adolescence a time for the individual's adjustment. During childhood preparation for and the adjustment to illness and treatment procedures is often about caregivers encouraging children to externalise the disease with techniques such as play therapy, imagery using toys and puppets, and drawing about thoughts and feelings. The responsibility of illness treatments is most commonly in the hands of parents during the developmental period of childhood. Parents are primarily responsible for treatment adherence, bear the worry of the future of their children and endeavour constantly to try to normalise family life around the child's illness care whilst balancing both the risk of non-adherence to treatment and the consequences of illness treatment activities on daily family life. Adolescence brings an expectation for young people to take over these responsibilities, but also a sense of grieving and fear for parents of losing control of their child's life and the constant threat of worsening illness. Nursing practice, although trying to promote opportunities for resolving the conflict of identity versus identity confusion and a sense of independence for young people with chronic illness, should not lose sight of the role and experiences of parents in health care. This is particularly important for adolescents still struggling to master previous milestones or those who may have regressed to previous stages whilst receiving health care. The situation of assuming a level of psychosocial development without a thorough assessment can be highly distressing and confusing for young people and their parents, and risk the therapeutic effect of illness treatments.

Treatment Adherence and the Chronically Ill Adolescent

Adolescence, as previously discussed, is a critical developmental period for conforming to youth culture and feeling a sense of normalcy among peers. Young people with chronic illness frequently see missing treatment as a reasoned trade-off to 'feeling normal' among peers. Whereas adhering to treatment responsibilities can compromise peer relationships and for some young people create a sense of isolation from peers, a feeling of loneliness and confusion about who one is in the world can lead to identify confusion (Boice, 1998). The risk of identity confusion and a sense of loneliness are frequently magnified for young people who have to spend extensive periods of their adolescence in hospital. This situation emphasises both the need to understand developmental mastery for adolescents with chronic illness, but also the importance of creating opportunities in health care to facilitate peer experiences and allow for a sense of individuality. Recognising the links between understanding adolescent psychosocial development (in the context of childhood developmental masteries as a critical mediator of adolescent developmental outcome) and optimising both developmental mastery and health outcome are critical to the efficacy of the healthcare interventions during adolescence in the context of the often life-threatening acute exacerbations of chronic disease. I have raised this link here and will now go on to discuss psychosexual development as ground work to bring together these ideas and the importance of well constructed healthcare interventions for chronically ill adolescents. The critical understandings, which have been raised here, will be illustrated and discussed further , using case studies, later in this chapter.

Psychosexual Development, Sexual Health, and Reproduction

Parents, and often strangers, become involved in the daily activities of physical care, in conflict with the innate urge for independence and privacy during adolescence. The psychosexual development of young people with chronic illness is also vulnerable during adolescence. Sexual behaviours are socially learned and shaped by experiences within the family, the peer group, and the society (Berk, 1991). Sexuality is a natural and important aspect of human identity, integral to self-concept and often compromised or confused by illness, disease treatments, and disability. Illness and disability may disrupt or confuse relationships with others, but do not diminish the life long need to be close to people or prevent an emerging sexuality during adolescence (Lubkin & Larsen, 1998). The ramifications of chronic illness on sexual development and functioning can be concerning for young people and their parents.

Children and young people with chronic illness and/or physical disabilities are widely perceived to be childlike and asexual without the same sexual impulses as their well peers (Lock, 1998; Suris, Resnick et al., 1996). Consequently, little consideration is given to the emerging sexuality of chronically ill children and adolescents (Schor, 1987). Further, the personal and sexual development taught by parents and educators to understand protective behaviours might be overlooked during long periods of hospitalisation and absence from school and family life. Children and young people with the psychological and physical disabling effects of illness are much more likely to be sexually abused than their well peers (Muccigross, 1991; Schor, 1987). This situation emphasises the need for recognition and respect for the psychosexual development of young people with chronic illness and the importance of learning protective behaviours (Muccigross, 1991; Puukko et al., 1997).

The nursing literature rarely focuses on the psychosexual component of psychosocial development health and sexual functioning of young people with chronic illness. However, there are a few studies in the area, which highlight the need for nurses to have a thorough understanding of the psychosexual development of young people with chronic illness. Researchers exploring the sexual behaviours of 36 284 high school students used subsections of the data to compare and understand more about the sexual behaviours of students with chronic illness. Included in the study was a comparison of sexual behaviours between young people with visible illness versus those with invisible illness (Suris, Resnick et al., 1996). The findings indicated that the young people with chronic illness were at least as sexually involved as their peers, and much more likely to have been abused. No differences were found between the sexual activities of young people with visible signs of disease such as scoliosis and arthritis compared to invisible disease such as diabetes and seizures. The authors concluded that health practitioners and educators should discuss sex, sexuality, and protective behaviours with their chronically ill patients. Further, the authors advocated that the clinical milieu should encourage openness and respect for discussions about the subject (Suris, Resnick et al., 1996). I discussed earlier in this chapter the difficulties children experience in setting boundaries with strangers touching their bodies. It is reasonable to suspect that the difficulties experienced by children may be a precursor to later psychosexual developmental problems for some young people with chronic illness.

Given the longer life spans for young people with chronic illness, ensuring sexual health education and opportunities to discuss reproduction are important components to health care for young people with chronic illness. The psychosocial issues of 14 young women with cystic fibrosis concerning puberty and motherhood were investigated in a qualitative study (Johannesson, Carlson, Brucefors, & Hjelte, 1998). The researchers found that the women in the study felt socially accepted and not ashamed about their obvious delays in puberty. However, the study indicated problems with aggressive behaviour during puberty among the group as well as concerns about premature death, secret worries about sexuality and fertility, an avoidance of close relationships with young men and many concerns about mothering. Recommendations from the study were that young people with chronic illness, particularly girls, should receive information on puberty and fertility. The women interviewed felt they received little information about sex, puberty, and fertility from healthcare services (Johannesson et al., 1998).

A search of the literature, exploring the implications of a medical illness for adolescent psychosexual development and the role of sex education, found very few studies (Lock, 1998). The small amount of literature found by the review suggested that adolescents with chronic illnesses were under educated about sexuality, socially inhibited, and had various body image concerns (Lock, 1998). The reviewer suggested that clinical approaches and educative interventions need to be developed to address these specific concerns. The important role of family, peers, culture and society as other powerful mediators in the psychosocial development of chronically ill adolescents, surely more important than clinical interventions, was not discussed in the studies (Lock, 1998).

A reliance on health care to optimise the psychosexual development of young people with chronic illness can be more compromising to young people than the predicament of long periods in hospital and away from school and peers. A holistic view of developmental opportunities is required with healthcare interventions as an adjunct for missed opportunities. Young people with chronic illness still need to experience the normal highs and lows of adolescent experiences, peer relationships and risk taking behaviours despite the presence of illness, and the relative protective isolation from the 'real world of adolescence' during long periods of hospitalisation.

Risk Taking Behaviour

Young people with chronic illness are also perceived not to experiment with risk taking behaviours common to adolescence such as alcohol and drug use. Britto et al. (Britto et al., 1998) surveyed 321 adolescents aged 12 to 19 years, with cystic fibrosis and sickle cell disease, to determine the prevalence and age of onset of risky behaviours. These young people were compared with a group of matched healthy peers. Overall, the adolescents with cystic fibrosis and sickle cell disease reported less lifetime and current use of tobacco, alcohol and other substances, less weapon carrying, less drink driving and more seat belt use than their well peers. However, 21% of adolescents with cystic fibrosis and 30% of those with sickle cell disease reported frequent tobacco use and early sexual intercourse, higher rates than expected by the researchers (Britto et al., 1998). The researchers emphasised the need for psychosocial screening and harm minimisation education to be incorporated into the routine health care of adolescents with chronic illness.

Suicidal thinking and self-harming behaviours are frequently associated with the developmental period of adolescence and associated with, or seen to be a consequence of, struggles achieving a sense of identity and the experience of identity confusion. Suicidal and self-harming behaviours are increasing among young people with chronic illness. There is evidence of suicidal behaviours among chronically ill young people (Rosina et al., 2003; Ruzicka, Lado, Choi Ching, & Sadkowsky, 2005; Vajda & Steinbeck, 2000). Depression is considered the highest predictor of suicidal behaviour across all age groups (O'Connor, Armitage, & Gray, 2006).

The presence of depression and suicidal behaviour in the context of a chronic physical illness is increasing (Ruzicka et al., 2005). Druss and Pincus (Druss & Pincus, 2000) interviewed 7589 people, aged 17-39, as part of a national survey. The interviewers collected information using a checklist of common medical conditions and a self-report questionnaire about depression and suicidal behaviour. The findings indicated that conditions such as cancer and asthma were associated with a more than fourfold increase in the likelihood of a suicide attempt (Druss & Pincus, 2000). A study by De Leo et al. (1999) attempted to identify psychosocial characteristics that might predict suicidal behaviour among 1269 young people aged 15 and over after suicide attempts. The findings indicated that one in two of the subjects suffered from an acute, chronic, or a chronic disorder in relapse, at the time of the suicide attempt. These studies, despite the large sample sizes, did not specify the types or severity of illness or the age distribution. However, the findings have profound implications for health services, particularly in Australia, where suicidal behaviour amongst the young is prevalent. The importance of including bio-psychosocial assessment, with an emphasis on risk taking behaviours, is highlighted by the findings of this study.

Nurses can detect early indicators of distress and depression among chronically ill young people (Valente, 2001). The sensitivity of assessment tools will need to be considered so that the tool can identify early indicators of persistent anxiety, overwhelming sadness, poor coping and suicidal thinking rather than consequences such as depression and suicidal intent. Generally, such assessment tools are not used as first line assessment in general hospital chronic illness health care, but as a screening tool once the signs of depression and suicidal thinking or behaviour are suspected. Current tools to measure mental health in clinical practice are orientated toward the identification of the presence of psychopathology and appropriate treatment pathways rather than early warning signs and appropriate interventions, although this is improving with the advent of early psychosis screening (Cosgrave, 2000). There is a wealth of literature supporting early intervention in adolescent mental health but the use of appropriate screening tools in adolescent chronic illness health care is yet to be accepted. The other issue is that there are normal levels of suicidal thinking, anxiety, and sadness that, for some young people, are important in the developmental work of resolving the conflict of identity versus identity confusion.

The challenge for young people with chronic illness, and a confronting issue for carers and clinicians, is the question of what is a safe level of risk-taking behaviours or risk-taking that does not lead to exacerbations of illness or have a compromising effect on the treatment interventions or compromise to adolescent developmental task of resolving the conflict of identity versus identity confusion. Adults frequently focus their concerns around the problematic treatment adherence of adolescents, but are often avoidant of the struggles inherent in adolescent development. For some young people with chronic illness risk-taking behaviours, unresolved grief, persistent anxiety, and depression are not as recognisable as in the physically well young person. Chronically ill young people may miss appropriate support through the usual struggles of adolescence and/or miss appropriate treatment for mental health problems that often emerge in adolescence. This situation may lead to a poorer resolution of the conflict of identity and identity confusion, an elevated risk for mental illness and in the context of difficulties with treatment adherence, can increase exacerbations of illness and poorer health outcome.

Illustrating Responsive Nursing Practice: Case study of Ellen

I will use the case study of 'Ellen' to bring the challenges, risks and opportunities for adolescent development together to highlight the importance of healthcare that includes a thorough understanding of adolescent development and a consideration that the young person and their family are critical members of the team. 'Ellen' is a 16-year-old young woman with cystic fibrosis. The treatment of cystic fibrosis for 'Ellen' includes physiotherapy three times a day, nine enzyme replacement tablets with each meal as well as nebulised medicines twice daily and an average of four hospital admissions each year. 'Ellen' preferred to keep her illness a secret from her peers. She had an earlier experience with a young man who, when he learned 'Ellen' had a terminal inherited disease, did not want to continue seeing her. The young man believed 'Ellen' might die during sexual intercourse, or worse, that she might become pregnant and the disease would affect the child. 'Ellen' has dreamt of having a husband and children before she dies. 'Ellen' also had concerns she might be 'gay' and this was the reason men rejected her. 'Ellen's' illness has prevented long-term friendships with peers. The experience of being called a 'freak' following a prolonged period of coughing has forced 'Ellen' to fabricate stories to prevent disclosure of illness to her peers. 'Ellen's' family was quite over-protective. The family provided most of 'Ellen's' health care at home and during admissions to a paediatric hospital. At the age of 16 'Ellen' was told her next admission would need to be at the local adult hospital; Ellen progressed through the hospital's transitional care program to the adult healthcare services but she held reservations about an adult hospital admission.

'Ellen' was admitted to an adult hospital with a chest infection, her first to an adult hospital. She was very anxious about the admission, resisting until she was very ill. The adult hospital encouraged a high level of independence and a high level of self-management was expected. Some two weeks into the admission, 'Ellen' became aggressive and refused or delayed her medications and became almost childlike in her dependency needs. The nurses were surprised and somewhat annoyed to see 'Ellen's' parents bathing and dressing her after they had insisted she self-care. Comments from nursing and medical staff included: 'Ellen' was manipulative, immature, lazy, cared little about her health and her parents perpetuated the situation. Later psychosocial assessment revealed that in fact 'Ellen' was preoccupied with thoughts of her death as an adult and associated the adult hospital with the end of her life. 'Ellen' preferred to have her parents provide total care particularly when she was unwell, feared close relationships with adults, especially her peers, and had had thoughts of suicide using her own medication. 'Ellen' felt quite protected in the assuming the behaviours of a younger developmental stage.

Many unresolved developmental conflicts are clearly evident in 'Ellen's' story: struggles with dependence and independence, identity issues, concerns about her sexuality, fears about intimacy and overprotection by understandably very anxious parents with significant enmeshment. 'Ellen's' parents preferred to maintain her dependence to protect her from growing up and having to take care of herself, knowing that she will only get sicker as she gets older. 'Ellen's' father commented on the difficulties of caring for Ellen, 'at least we have got her this far and there is no point building her up for a life that is not possible, she was fine until we brought her here'. 'Ellen' confided that adult hospitals expected people to look after themselves, even when people do not look after themselves at home. She felt self-care was too difficult and staying a child kept the family happy. Clearly, these views are understandable responses to an increasingly difficult situation for 'Ellen' and her family. Ellen and her family refused to see a psychiatrist or other 'shrinks, they will only make it all worse'.

The regularity of the hospital admissions and outpatient clinic visits for 'Ellen' and her family provided an opportunity for support, including the final acceptance of a referral to the adolescent consultancy team at the hospital. Subsequent psychosocial and mental state assessments identified high levels of anxiety, longstanding depression, and suicidal ideation. Collaboration between the adolescent team Clinical Nurse Consultant, the respiratory physician, and respiratory Clinical Nurse Consultant and a community youth counsellor enabled treatment for depression and ongoing counselling. 'Ellen' agreed to attend the hospital adolescent group room to mix with other young people with chronic illness and to continue her schoolwork. Debriefing and group clinical supervision was also extremely valuable for the nurses caring for 'Ellen'.

'Ellen's' family were her closest and strongest supports and eventually, as the nurses came to understand the complexity of the parent/child relationship, the nursing staff became supportive of both 'Ellen' and her parents. Even more importantly, the nurses understood how to support the family as a unit, in what became a nurse/interdisciplinary team/family relationship. The role of the family working in collaboration with the nurses was invaluable to the psychosocial aspects of her care. Completion of the tasks of adolescent development and the resolution of earlier developmental conflicts for 'Ellen' may not occur until she is well into her twenties or thirties, with total independent functioning most likely impossible. A family therapist was eventually accepted to explore feelings of guilt, grief, and loss that had persisted for many years, preventing any sense of hope or normalising of family life. Cases such as 'Ellen's' are complex, with the effects of the illness and treatment in conflict with the normal trajectory of psychosocial development and, clearly, the expectations of others. For these cases, health services may not have a right to decide what is right or wrong given the terminal and severe disabling nature of many chronic illnesses, such as cystic fibrosis and cancer. Perhaps what families need from health staff is respect and acceptance for their predicament and the offer of supportive opportunities to meet current developmental needs rather than an assumption of what the young person should be able to achieve and an expectation of the role of parents.

The developmental environment for many young people with chronic illness is dominated by hospital experiences. These experiences have the opportunity to inhibit or facilitate developmental task mastery. Nurses with their ongoing contact with chronically ill young people and their families are influential in the healthcare context of the young person's developmental world and they need a thorough understanding of adolescent psychosocial development and risk assessment. Moreover, nurses are perfectly placed to identify young people struggling with psychosocial development whether represented by treatment adherence or difficult and/or at-risk behaviours. However, given Ellen's story, it is sometimes difficult for nurses to accept that at times psychosocial nursing interventions are most appropriately aimed at adding dignity and respect to a clinical milieu, rather than promoting developmental mastery.

6.Intimacy Versus Isolation – Early adulthood (20s and 30s) and the sick young adult

Erikson's sixth stage of psychosocial development, spanning the years of the twenties and thirties, the final stage for the focus of this discussion, involves the conflict of intimacy versus isolation (Erikson, 1968). The resolution of this stage is achieved with the establishment of a meaningful life, with a sense of connectedness to other people. Erikson describes this stage as finding oneself, yet also losing oneself in another person (Erikson, 1968). Young adults unable to resolve this conflict are less able to establish close relationships, often fearing rejection, isolating themselves from other people.

Young adults during this developmental period predominately focus on seeking a career and developing intimate relationships with other people. The major developmental task at this stage is a psychological readiness and a commitment to mutual intimacy. This level of intimacy prepares the young adult for marriage or its alternatives to attain and retain individual identity within joint intimacy (Erikson, 1968). If the young adult finds satisfying friendships, but is also able to achieve intimacy with another, the negative resolution of social isolation will be avoided (Erikson, 1968). A negative resolution results in the young person being unable to establish close relationships, increasing the risk of social problems and relationship difficulties (Erikson, 1968). For some young people with chronic illness, the ability to have an intimate relationship whilst remaining largely physically dependent on parents or carers is extremely difficult and most likely impossible. This situation may be a result of longstanding poor self-esteem and confused sense of identity, a fear of rejection and a sense of hopelessness (Andrews & Brown, 1995; Puukko et al., 1997).

A sense of self-esteem is crucial to the achievement of satisfying personal relationships (Christian, 2006). Ritchie (2001) explored levels of self-esteem and hopefulness among a group of young people with cancer. The findings showed a strong correlation between the constructs of self-esteem and hopefulness (Ritchie, 2001). Additionally, the findings indicated that nursing interventions targeting self-esteem could improve hopefulness. I have discussed the particular challenges for children and adolescents with chronic illness in resolving the conflicts of Erikson's tasks of adolescence. However, I have yet to discuss the specific challenges for young people diagnosed with chronic illness during the course of adolescence or young adulthood. The experiences are similar to those young people with chronic illness since childhood but different in some specific ways.

Illustrating Responsive Nursing Practice: Case study of Samantha

The case study of 'Samantha', a young woman diagnosed with cancer as a young adult, highlights the experience of losing developmental mastery when challenged with a chronic illness; she found herself seeking the safety of older more child-like ways of coping with the treat of illness and death.

'Samantha' was faced with a sudden diagnosis of cancer at 20 years of age. Her story highlights the risks and vulnerabilities of cumulative poor developmental task mastery or a regression in developmental mastery. 'Samantha' tells her story of recovering from cancer and how 'the getting better almost broke me' (Miles, p. 32, 2000). 'Samantha' believed her difficulties began, not when she was given the cancer diagnosis or during treatment, but when the cancer was considered medically cured. Samantha felt her problems centred on a loss of identity and not being able to see a future of how to be in the world. She was not the person before the cancer emerged, not the heroic person enduring cancer, but another person who had to get back to normal, whatever 'normal' had now become (Little, 2003). When the cancer re-emerged with a secondary growth, 'Samantha' felt more confident and was relieved to return to the identity of the cancer patient, receiving great support and respect from all around her. Once reluctantly, 'cured' again, 'Samantha' began to experience outbursts of temper, punished herself with work, and refused to eat or to comply with after cancer care (for example medications, routine blood tests etc) (Little, 2003). She was unable to share her feelings with anyone, as she felt that they would believe she was ungrateful for having survived the cancer. Over time 'Samantha' began to develop a new identity and to move on from a state she called 'perpetual whimpering' without wishing the cancer to return. 'Samantha' asks, 'why does the system build you up to be a hero while you are sick, without preparing you for the fall, when you get better?' (Little, 2003).

Little, Sayers, Paul, and Jordens (2000) define this time of identity confusion and relative safety with the cancer label as a state of liminality. Liminality is a term that comes from cultural anthropology, and refers to a state of feeling 'betwixt and between', rather like a social initiation to a new life. The state of liminality occurs when the individual feels they cannot identify with the person they were before the cancer, but feel a sense of fragile security in the identity of a cancer sufferer (Little et al., 2002; Little et al., 2000). This paradox of survival may be difficult to appreciate for those who have not had cancer, but are common feelings amongst cancer sufferers and survivors of cancer and other chronic illnesses (Little et al., 2000). The subgroup of chronically ill young people struggling with their psychosocial development and functioning, the concern of this thesis, may well be experiencing a state of liminality (Little, Jordens, Paul, Montgomery, & Philipson, 1998). The group may be experiencing a psychosocial developmental moratorium, a 'temporary dropping out', as suggested by Erikson (1968). Much more research will be required to understand the impact of chronic illness on psychosocial development and functioning.

Historically, many people with cancer and other life threatening diseases died soon after diagnosis; therefore, the implications of survivorship were not a consideration for health care. Despite the increase in survivors, little information is available to guide families or clinicians in what to expect if the child or young person survives the threat of the disease (Little et al., 2000). Survivors of cancer and the chronically ill unable to emerge from a state of liminality with a sense of identity may remain in a state of psychological fragility, unhappiness, and existential angst for some time (Little et al., 2002; Little et al., 2000). In light of the number of cancers that can now be cured or at least the opportunity for long remissions from illness, clinicians have the opportunity to rethink the psychological management of young people and their families. Traditional strategies to rally cancer patients by psychologically transforming them to the prominence of a hero or martyrdom by support groups, films, the media, and society generally may not be entirely useful. For Samantha, the regression to previous developmental stages of mastery albeit after a great deal of distress had provided another opportunity to resolve the conflict of identity versus identity confusion and place her in a position psychologically to recommence the developmental stage of young adulthood with a new sense of identity. Samantha could then recommence her efforts with the conflict of resolving the conflict of intimacy versus isolation and move on with her life.

Despite the seeming endless developmental challenges for young people with chronic illness, many of this group adjust to life as a young person without significant difficulties. There is also evidence that the majority of young people adapt well to chronic illness. However, there is a subgroup of children and adolescents, who may develop a maladaptive response to illness (Patterson & Blum, 1996; Rosina et al., 2003; Stuber, 1996; Stuber et al., 1997). The subgroup may be those with greater illness severity or disability, some survivors of cancer or those young people with premorbid genetic or social vulnerabilities. This subgroup may be at a higher risk for, or be more susceptible to, psychopathology, particularly anxiety and depression (Burke & Elliott, 1999; Patterson & Blum, 1996; Stuber, 1996). Persisting anxiety and depression, either because of unresolved developmental crises or associated with the loss of previously achieved developmental milestones, may well be the antecedents of adult psychopathology (Erikson, 1968; Rossen & McKeever, 1996; Stuber, 1996; Stuber et al., 1997). A lifetime of chronic illness or a new diagnosis during the developmental period of adolescence or young adulthood brings some similar and other unique challenges. Clearly, a thorough understanding of psychosocial developmental mastery as the chronically ill young person presents for treatment and prior to the commencement of illness is critical to the efficacy and sustainability of health outcomes with markers that cut across both physiological and psychosocial domains.

In many ways, society itself is not helpful to young people with chronic illness. In a foreword to the book, Different But the Same (Cameron, 1996), a collection of narrations about living with serious illness by a group of young people, John Marsden states that society sentimentalises sick children and young people. In contrast, young people in normal situations, without illness or disability, are treated poorly by society and with little respect. Furthermore, he argues that it is only when children are 'in extremis' we freely lavish love and affection on them, while in other cultures they may receive it as a matter of course. Marsden challenges the reader, stating that the reality of young people who have serious illnesses is more complicated than the media has us believe, and that sending them to Disneyland may allay our guilt, but not our responsibility towards them. Marsden's comments have wide ranging implications for the treatment of young people with chronic illness, particularly in health care and generally in a society. Marsden highlights the responsibility of the society to care for these young people, not simply medically, but to provide the psychological care and respect for their developmental struggles.

Conclusion

In this chapter, I have analysed and discussed the impact of chronic illness on psychosocial developmental outcome, at each developmental stage from infancy to young adulthood. A more positive developmental outcome, or the ability of a chronically ill young person to resolve each developmental challenge as it arises, means the emergence of a coherent sense of identity, the achievement of optimal independent functioning and the ability to form satisfying relationships in young adulthood. A more negative psychosocial outcome may mean a persisting state of identity confusion with an increased risk of adult psychopathology (Daum & Collins, 1992; Erikson, 1968; Stanger et al., 1996; Steinberg & Avenevoli, 2000; Stuber, 1996). Developmental mastery at each particular stage is cumulative; each gain facilitates the mastery of the next developmental task, resulting in the best possible developmental outcome in adolescence and young adulthood. There is some evidence in the literature that psychosocial developmental mastery is important in coping with the ramifications of chronic illness for physical and emotional wellbeing (Hornsten et al., 2002; Kuhnle & Bullinger, 1997; McCauley et al., 2001). I argue that psychosocial developmental mastery is a vital component in the process of coping and adaptation to chronic illness and may be linked to better illness stability. Psychosocial development should be a major consideration in the development of nursing interventions for children, young people, and families affected by chronic illness.

The healthcare environment, in which nursing has significant agency, is highly influential in opening up opportunities for psychosocial developmental mastery and the identification of young people struggling with psychosocial health and functioning. Nursing practice and clinical leadership has a significant role and the opportunity to integrate psychosocial assessment and interventions into routine clinical practice. The monitoring of psychosocial health during hospital admissions or clinic visits can identify young people not coping with their illness and those with poorer psychosocial health. This level of practice development will enable early psychosocial interventions to be applied in general chronic illness health care and may reduce the risk of psychopathology.

Nursing, together with other disciplines, has a responsibility to understand better the psychosocial development of young people with chronic illness. This knowledge will assist in evaluating the healthcare milieu in terms of factors that inhibit psychosocial developmental progression and mastery. On the other hand, this evaluation can discover innovative ways to facilitate developmental opportunities. Without a thorough consideration of psychosocial development and current level of mastery for the young person, the hospital procedures, treatments and nursing/interdisciplinary interventions discussed in this chapter can compromise the progression of psychosocial development for young people with chronic illness. Nursing knowledge, leadership and practice development that is better informed about the psychosocial development of young people with chronic illness has the opportunity to optimise physical and psychosocial health outcomes, coping and adaptation to chronic illness. The question that remains incompletely answered is how to use clinical nursing leadership and clinical leadership activities, and in what context, to influence healthcare service model development and policy reform in ways that optimise bio-psychosocial outcomes for young people with chronic illness. In Chapter 8, I bring together a number of ideas about leadership and clinical nursing leadership activities to provide a deeper understanding and ways forward to participate in healthcare reforms.

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Chapter 9

The Chronic Illness Healthcare World: Conceptualising Nursing Leadership at Each level

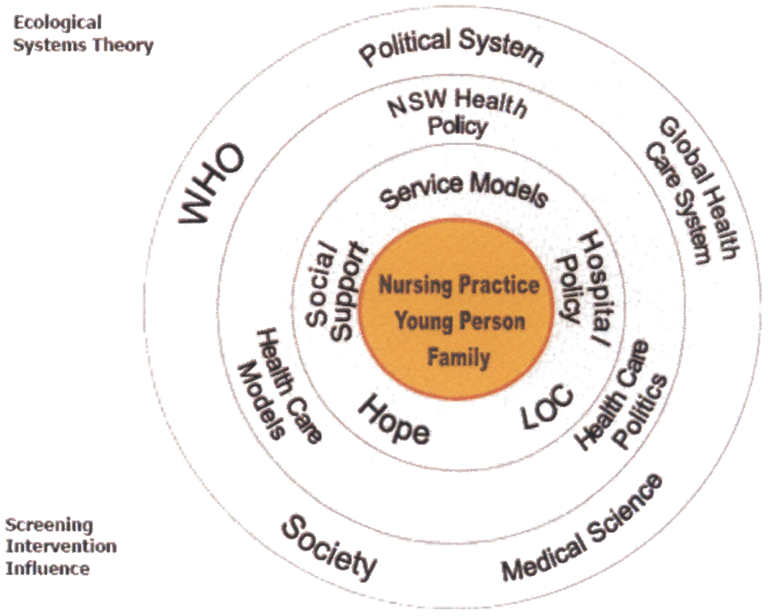

Diagram 8

Introduction

Throughout the work of my thesis, nursing scholarship development, clinical nursing leadership and clinical leadership activities from the perspective of a clinical nurse have emerged as powerful mediators of change in the healthcare world and the internal world of young people with chronic illness. Along the way, a few questions have remained incompletely answered that would benefit from further discussion in regard to nursing leadership, and how to use it. Ecological Systems Theory (EST) has proved to be an effective framework for organising the complexity of the healthcare world of young people with chronic illness and the roles of nursing scholarship and leadership activities to optimise outcomes. My aim in this thesis has been to extend knowledge about the psychosocial development of young people with chronic illness, to enhance the responsiveness of nursing scholarship with frameworks for practice and clinical leadership activities within the context of an adult hospital. Throughout each component of my work, the critical issue of leadership, and in particular the clinical leadership required from nursing, has been evident.

This chapter sets out potentially achievable leadership strategies and clinical leadership activities that can influence responsive policy reform at each level of the healthcare world. I emphasise that the discussion and the strategies presented in this chapter are from the perspective and scope of experience of a clinical nurse, to enhance the capacity of clinical nurses to participate in, and contribute to, the policy development world of health care. The aim of this level of skill development for a clinical nurse is to improve the responsiveness of service models and the efficacy of care for young people with chronic illness. The intention of this chapter is not to present a broader discussion about nursing leadership, or the power issues within the healthcare world, or barriers to nursing leadership activities (although the barriers and power issues are acknowledged as important) but, more specifically, to explore what the clinical nurse can achieve by bringing practice scholarship to policy reform. My intention in this chapter is to provide further explanation of leadership and specific leadership activities for clinical nurses.

I have touched upon some of the challenges in relation to nursing leadership throughout the thesis. However, within this chapter, I will revisit and extend some of those discussions. I will identify what types of leadership, what leadership activities are required at each level of Bronfenbrenner's framework, and what specific activities, relevant to my field, are necessary to optimise outcomes for young people with chronic illness.

The use of EST is extended in this chapter to analyse nursing leadership in the context of nursing young people with chronic illness. I have selected literature pertinent to the discussion about leadership and clinical leadership activities at each level of the framework. I have argued throughout the thesis that the positioning of nurses and the fact that they practise 24 hours a day, seven days a week in the clinical care of the chronically ill, places nursing in a position to provide leadership in policy reform and responsive practice development. Within this chapter I argue that exploiting this context for leadership activities can inform policy reform at higher levels and interpret policy into practice development at lower levels of the healthcare world, and thereby resource patients to lead themselves to better health.

The concept of nursing, sometimes referred to as clinical leadership, as well as leadership generally, is often confusing for nurses. Firstly, nurses often ask what is clinical leadership and how does it work? Secondly, they ask in what contexts can clinical leadership be used to enable nursing to have an appropriate and sustainable voice in healthcare reforms and clinical practice development.

Nursing Leadership

Issues of Power in Nursing Leadership: Barrier or strategy

For nurses, the issues of power and powerlessness have been barriers to the nursing profession utilising its knowledge and research evidence to inform policy reform and practice development. There appears a level of acceptance across society, health care, and government that healthcare decision-making and reform is to remain under the medical sphere of influence (Chiarella, 2002). This situation has maintained significant barriers for nurse leaders to participate in healthcare reform. Antrobus (2004) argues that nurses can be taught skills to engage successfully in healthcare politics. Nurse leaders need sophisticated political skills to implement policy, influence planning strategies within organisations and to utilise research evidence to improve clinical practice (Antrobus, Masterson, & Bailey, 2004). It is reasonable to consider that nursing leadership and political skills are important to nursing, whether working in the practice areas or within management and political contexts of the healthcare world. What has not been clear to nurses is what sorts of leadership activities enable nurses to achieve influence at the political level of health care that can then be interpreted into the practice world to optimise patient outcomes.

There is no doubt and it would be naïve to discuss the role of nurses in healthcare politics and nursing leadership activities without acknowledging the power imbalance for nurses in healthcare politics. The situation of the medical profession constantly resisting nurses to achieve equal power as well as the slow up-take by nursing to prepare nurses in political acumen has allowed a system of dominance and power inequity in policy reform to remain (Antrobus et al., 2004; Chiarella, 2002). However, I have chosen to acknowledge these barriers but not to discuss them in detail, as I wish to focus on some potentially achievable strategies for the purposes of this work. The EST framework allows discussion of nursing leadership and leadership activities at different levels of the healthcare world and the links between each level. I begin the discussion of nursing leadership and leadership activities in this chapter with the practice level of the healthcare world alongside my career as it progressed into nursing management and leadership roles.

As I began my doctoral studies, my position in the healthcare world was a clinical role providing direct patient care. Throughout the course of my work, I have moved from clinical nurse consultant roles to management and formal leadership positions. This movement occurred concurrently as I worked on my thesis, specifically the analysis of different levels of the healthcare system. As a result, I have developed a deeper understanding of nursing leadership, particularly in terms of developing nursing leadership activities. My doctoral work has been concerned with making sense of the healthcare world to find ways to ensure practice knowledge leads to policy reform that leads to greater opportunities for young people with chronic illness to optimise not only their biological, but also their psychosocial, health outcomes. .

My interest, in terms of nursing leadership, has been about how to empower and/or enable nurses to look beyond the medical needs of young people with chronic illness to their psychosocial needs and thence how to contribute to responsive healthcare reform and practice development. Using EST to analyse the healthcare world at discrete levels has made me realise that, if nurses want to successfully impact on how care is delivered by the groups with whom they work, there is a need to exert influence at every level of the healthcare system. Leadership activities are required at each level of the healthcare system to ensure informed, responsive policy, and practice development.

In this chapter, I do not intend to provide a systematic review of leadership theory or to present a comprehensive leadership strategy. What I will do is bring together a number of ideas about leadership and suggest potentially achievable leadership activities, from the perspective of a clinical nurse to influence healthcare reform. In addition I will explore which areas of the healthcare world might require greater or different types of leadership for clinical nurse to engage in and what sorts of activities would be most useful. I begin this chapter with a brief discussion of the understandings of leadership generally, with an emphasis on the role of clinical leadership. The question I wish to explore is what leadership activities are required to optimise the clinical care of young people with chronic illness at each level of my framework of the healthcare world?

Different Types of Leadership

The leadership literature is prolific, with definitions of leadership and the important qualities of leaders abounding. Leadership is frequently defined as an influential relationship among leaders and followers who intend real changes with shared values (Cain, 2005; Hitt, 1993;

Rost, 1993). Early leadership research established widely accepted leadership models with three discrete styles (Lewin, 1948). Firstly, the autocratic leader wields a strong level of authority, makes most decisions, has a very directive style, and fosters dependency among followers. Secondly, the democratic leader is much less controlling, offers suggestions to solve problems, plans strategies with a group, participates in the work of the group, and fosters independence. Finally, the laissez-faire leader has no control over followers, is very non-directive, avoids decision-making, is largely uninvolved with the group, and fosters a chaotic context for work (Lewin, 1948). These specific leadership styles are recognisable in the healthcare world today but arguably have achieved little beyond nursing operations to influence healthcare reform and practice development.

Despite the clinical expertise of nurses and the public confidence in nursing as a profession, nursing leadership has rarely been central to policy and practice development (Mechanic & Reinhard, 2002). It may be that a gap exists between practice scholarship and the policy reform contexts of healthcare. This weakness, either in the capacity to influence policy development, or general relatedness, compromises the effectiveness and sustainability of nursing leadership at each level of the healthcare system. This is particularly evident in the difficulties the profession experiences in contributing to healthcare reform (Antrobus & Kitson, 1999; McCormack, Manley, & Garbett, 2004; Rafferty & Traynor, 1999). Policy development needs to become a core function of nursing leadership activities but nurses are largely not welcome at the policy table and have a relatively weak power base (Hughes, 2003). Nurses often put a great deal of energy into policy reform activities and become frustrated when there is no outcome (Hughes, 2003). This situation is a significant factor that compromises responsive policy reform and practice development in the chronic illness healthcare world; particularly in raising the specific issues of the chronically ill and what is required to optimise bio-psychosocial health outcomes for young people with chronic illness.

Nursing is undergoing a renaissance in thinking about leading staff in clinical work and how to develop leadership and political skills among nursing teams (Antrobus et al., 2004; Valentine, 2002). In particular, there is concern about how to contribute to healthcare reform and policy development in a way that brings about better healthcare outcomes for patients (Cook, 2001). Hannagan has argued that leadership is much more about motivating people to act in particular ways with flexibility, rather than leading staff toward static organisational outcomes (Hannagan, 1995). Trends in healthcare leadership style, particularly in nursing, are undergoing significant change, shifting from the more command and control approach to more transformational, visionary and facilitative styles (Bass, 1990; Tornabeni, 2006). Hannagan's view is particularly salient: that real and sustainable change in healthcare is about bringing vision and values to it that equate with a range of patient outcomes. In my field of work, the vision would be about responsive policy and practice development that drives measures of the best possible bio-psychosocial outcomes for young people with chronic illness. Flexibility in vision and health outcomes is vital in the area of chronic illness. Advances in medical science constantly alter what is the best possible outcome for a patient with a chronic illness, varying with each disease.

Leadership and Leadership Activities that Work

Traditional nursing leadership, in my view, has been more about leading change with an expectation that wielding influence or relying on direction from higher levels of the healthcare world was necessary, and that this would somehow achieve good health outcomes for patients at lower levels. This is not to say that work at higher levels of the system is not important or is misdirected. However, without patient perspectives, practice wisdom and clinical research evidence, the work is compromised and without true authority. Including the perspectives of patients and clinicians is not a new concept but it requires application in the area of young people with chronic illness in order to influence service models, policy and practice development which consider the psychosocial outcomes of this group.

The art of developing staff and healthcare interventions in ways that directly enable patients to lead themselves to better health outcomes fits with the descriptions and actions of clinical leaders that embrace a transformational leadership style. A transformational leadership style is frequently connected with the development of clinical leaders (Cook, 2001; Kakabadse & Kakabadse, 1999; Murphy, 2005). Early leadership research established transformational leadership as an approach that focuses on the individual needs of followers (Burns, 1978). The model of transformational leadership inspires individuals with optimism; actively shapes a responsive healthcare culture; encourages intellectual stimulation in the workplace; and fosters follower creativity rather than dependency (Tomey, 2000). The leader with these qualities becomes a role model with a strong vision of what is required for staff to realise better patient outcomes (Tomey, 2000). The characteristics of effective leaders are required in all nursing roles rather than specific leadership positions. The transformational leader has many attributes in common with what is described as an effective clinical leader.

Clinical Nursing Leaders and Clinical Nursing Leadership

Characteristics of Effective Clinical Leaders

Convincing research evidence to identify the characteristics or attributes of clinical leaders is hard to find. The available literature is so diverse in methodology and research contexts that it makes definitive conclusions difficult. However, there is some agreement that successful clinical leaders have the following characteristics:

1. The ability to work as a change agent
2. Demonstrate a patient centred approach to care
3. Engage others with a style that encourages confidence and motivation in clinicians as individuals and as teams
4. Display integrity and are clinically competent
5. Have a flexible approach to work and innovative practice
6. Model self-management
7. Value networking relationships within and across interdisciplinary teams and external agencies

(Cain, 2005; Cook, 2001; Cunningham & Kitson, 2000; Stanley, 2004)

Much of the literature defining clinical leadership is opinion based or derived from the findings of small studies. There is little guidance about how to bring these qualities or actions into practice and how they relate to better patient outcomes. Practice development research, albeit in its infancy, is beginning to address this work. However, without such research, which may be the next step for nursing, this work will resemble or rapidly become rhetoric. For example, 'patient centred care' as a component of clinical leadership, is stated without any clear plan of how to involve the patient, or the patient's perspective, in care planning and service evaluation.

The Role of a Clinical Leader and the Dimensions of Clinical Leadership

The role of a clinical leader also varies across the literature. However, there is some consensus that the role includes coordinating, designing and implementing clinical practice across a group of patients; challenging practice; providing clinical advice, mentorship and coaching to other clinicians (American Association of Colleges of Nursing, 2003; Ham, 2003; Stanley, 2004). As part of the Royal College of Nursing Clinical Leadership Development Program the dimensions of clinical leadership that were improved by the program were explored and analysed by 28 clinical nurse participants. The nurses were asked at the end of the 18-month program to identify the dimensions of clinical leadership that indicated their individual skill improvement. The results indicated a number of areas of clinical leadership where this group felt they had improved their individual clinical leadership abilities. These areas included attending to the needs of the self; managing the team; patient centred care; networking; and becoming politically aware (Cunningham & Kitson, 2000). The components of clinical leadership identified in this program are important outcomes for developing clinical leadership skills.

In fact, there is a recent study of participants from a general hospital ward setting, who were involved in the development of a clinical supervision program. The aim of the program was to improve clinical leadership (Johns, 2003). The participants felt their leadership abilities had improved but were held back or resisted by the organisational culture. Johns (2003) believes clinical leadership programs have the same outcome as clinical supervision programs and the same barriers apply to sustainable clinical leadership. Antrobus (1999) believes nursing will require effective clinical leaders to translate policy into patient care and patient care into policy to realise better health outcomes for patients. This may be true, but nurses will need other leadership skills to traverse the policy – practice gap in the healthcare system.

Further Refining the Definition and the Role of Clinical Leaders

The efficacy of clinical leadership has been acknowledged as an important cornerstone to the influence the profession has at higher levels of the system (Johns, 2003). However, some disagreement exists about the role and positioning of clinical leadership, which needs to be discussed. The disagreement that concerns me most is the placement of clinical leaders and leadership activities away from the patient, invested in more supervisory, coordinator or resource person type roles (American Association of Colleges of Nursing, 2003; Wood, 2005). A review of the clinical leadership literature revealed a preponderance of anecdotal and opinion led papers with few experimental or empirically based studies reported (Cook, 2001). More recent analysis, attempting to define the role of clinical leaders, has found the situation unchanged. The role of clinical leader and positioning of leadership activities is confusing, remaining somewhat hierarchical, with little difference from a nurse manager role, and set apart from patients and patient care (Erickson, 2005).

Peters and Waterman in their classic research identified a framework of leadership that is highly suitable to further define clinical leadership, and leadership activities generally, in nursing (Peters & Waterman, 1982). They established a set of principles for effective leadership of highly successful American companies. These principles include having a bias for getting things done, advocating for what is important, positioning oneself close to the customer, possessing an autonomous and entrepreneurial approach to service and a clear vision for productivity through people; creating and sharing values across the organisation; sticking to the knitting (ensuring service always equates to today's customers needs); and implementing organisational structure that is simple, promotes innovation and can tolerate failure (Peters & Waterman, 1982). There is great appeal in applying this definition of leadership to the role and activities of clinical leaders in the healthcare world of young people with chronic illness. I will now continue this discussion to identify specific leadership activities at each level of my conceptual framework of the healthcare world.

Clinical Nursing Leadership Activities at Each Level of the Chronic Illness Healthcare World

I have argued that different sorts of leadership and leadership activities are required at different levels of the healthcare world to achieve the necessary policy and practice development I have recommended throughout my thesis. I now discuss what sort of clinical leadership activities are required at each level of the healthcare world that may potentially lead patients or, more specifically, to resource patients to optimise their own bio-psychosocial health outcomes. I begin the discussion of what specific clinical leadership activities are required in my field of work within the microsystem level of my framework of the healthcare world. For the purposes of this chapter the discussion will only include the features of each level of the framework relevant to the perspective and scope of a clinical nurse and specific clinical leadership strategies and activities that might bring the practice development I have recommended throughout my thesis to the level of healthcare and policy reform.

The Microsystem and Clinical Leadership Activities

The microsystem level of the healthcare world contains the internal world of young people with chronic illness and their families, and nursing practice. The clinical leadership activities required at this level of the framework cluster in three specific areas. Firstly, there is a need for a new vision of health outcomes for the chronically ill that will necessarily change the culture of care for young people and their families, particularly in adult hospitals. Secondly, it is necessary to bring theoretical knowledge about the how young people cope with chronic illness and the psychosocial development of young people into adult and paediatric nursing education at undergraduate, post-graduate and to professional development programs (in-service). Finally, responsive practice development is required to establish regular psychosocial assessment and developmentally facilitative nursing interventions within chronic illness nursing and interdisciplinary models of care.

The experience of chronic illness and responsive healthcare interventions will always be about managing symptoms and preventing complications with the aim of increasing survival years. Health outcomes for young people with chronic illness, and probably for chronically ill people of all ages, need to include psychosocial outcomes that are meaningful and satisfying. This approach will ensure that all endeavours should bring together the acumen of patients, clinicians, and other leaders at all levels of the healthcare world to develop responsive policy reforms and practice development. What is required is a vision of healthcare interventions that can optimise bio-psychosocial health outcomes for young people with chronic illness. I will utilise an example from my clinical work to illustrate the importance of using vision in clinical leadership activities. The following illustration is drawn from my clinical work as a clinical nurse consultant in adolescent health with an Adolescent Health Consultancy Service in a very traditional adult hospital.

The aim of the service, as described in Chapter 1, was to change the culture of care in an adult hospital to consider the developmental experiences and psychosocial outcomes for young people with chronic illness. The service raised funds and created an adolescent group room, named 'our space in this place' by the young people treated at the hospital. The young people spent time in the room between treatments doing schoolwork, passing time with peers, and participating in groupwork around resilience building activities often related to their illness. Initially, the work aimed at changing the adult culture of care to become more youth friendly. The work was going quietly, when quite unexpectedly the hospital organised a grand opening for the room. As a result, referrals to the service, mainly of young people whom nurses or doctors identified as not coping with their illness or those who simply needed to spend time outside the ward, began to steadily increase. The hospital slowly began to include appreciation of the needs of young people with chronic illness into many hospital policies and ward protocols, with little direct intervention by the service. A shared vision and meanings about work outcomes motivate people to 'stick to the knitting' (Peters & Waterman, 1982) even when day-to-day realities at times overwhelm the vision. This example illustrates the power of bringing vision to the work of changing the culture of health care.

Throughout this thesis I have argued that some young people with chronic illness have more difficulties coping with chronic illness and the impact of illness on an adolescent lifestyle. Many of these young people present with problematic treatment adherence and/or stereotypical difficult adolescent behaviours. Underlying psychosocial problems, often early indicators of distress, may be missed in the medical model of care. On the other hand, normal adolescent behaviours, such as challenging health advice, may be misunderstood or considered to be undermining the treatment plan or hospital routine. This often results in a punitive response from healthcare staff as illustrated in Chapter 8. Such a situation, particularly given the connections between physical and psychosocial wellbeing, may compromise bio-psychosocial health outcomes for this group.

A practical approach to psychosocial screening using the Home, Education, Activities, Drugs, Sexual Health and Suicidality (HEADSS) assessment is well established in adolescent general practice (comprising questions about home/family, education/literacy, activities/friends, drug use – prescribed or illicit, sexuality/sexual health and suicidal thinking, low moods or self harming behaviours) (Goldenring & Rosen, 2004). The process is simply asking questions on a number of themes known as points of vulnerability or strengths for young people. The important outcome of routine psychosocial assessment is for the nurse to make a decision about the psychosocial status. Specifically, the nurse should be able to ascertain whether a referral is required to a specialist service or specific interventions are needed for high-risk behaviours. On the other hand, issues may be identified that do not require a referral but need to be addressed in the nursing care, such as a feeling of dependency on parents and hospital staff, or problems with peers, particularly about physical differences and treatment adherence at school.

The practice development described here requires significant clinical leadership. The introduction of psychosocial screening to nursing practice would require change to the model of chronic illness health care. For this to occur the importance of psychosocial health and its relationship to physical health status would need to be fully appreciated. The work needed to achieve this sort of practice development would involve identifying the issue or clinical problem using literature and/or clinical research evidence, raising the discussion at clinical meetings and establishing a coalition of support among the interdisciplinary health team. The next step would be to present a succinct but well supported proposal to the clinical governance committee, practice development committee, or equivalent leadership body within the hospital. It is always useful to be prepared for opposing views such as time constraints, the notion that psychosocial assessment is not nursing work, and the implication that it may be transgressing clinical boundaries. These views surround nearly all aspects of nursing research and practice development (achieved by nurses) and are surmountable, but they are nonetheless powerful barriers to outcome. The activities of clinical leadership at the microsystem level or practice level of the healthcare world emphasise using vision to change the culture of care and evidence to lead practice development. I have briefly given two examples of clinical leadership activities at the practice level to illustrate leadership activities and outcomes that potentially could improve health outcomes for young people with chronic illness. These activities require further leadership to ensure practice change is sustained by responsive healthcare policy. The role of linking leadership activities to higher levels of the healthcare world is critical to ensure responsive policy reform to sustain effective practice development.

The Exo and Meso Systems and the Interlinking Role of Clinical Nursing Leadership Activities

Practice development, one major outcome of clinical leadership, is frequently also an outcome of change management processes, but it is of little value unless sustainable. In other words, unless the practice development initiative or healthcare culture change is linked to specific policy reform it is not sustainable. What is required in chronic illness care is the ability of clinical leaders, or change agents, to move up and down the healthcare world linking clinical practice development to policy development and vice versa. This endeavour involves translating both the patient's perspective and clinical practice into the language of politicians and policy writers (McCormack & Garbett, 2003). A group of 60 nurses interviewed in focus groups described this work as situating themselves between top management and the practice area, working within and outside the organisation. The nurses characterised the activities as 'top down' work, including interpreting and disseminating policy documents from higher levels of the organisation to the clinical and patient world. Other activities were described as 'bottom up' work, which involved generating interest in project work; developing opinion leaders to promote the need for change; representing the clinical area on committees; and networking across other services. The nurses in this study commonly saw themselves as working in-between management and clinical practice. They used deliberate strategies such as being seen around, making a point of meeting people, smiling at people and becoming known. These strategies ensured that nurses became important to the work of change and part of the process of change. Other more formal activities included representing nursing on committees with managers, members of other professions and service users (McCormack & Garbett, 2003). In my view, these nurses were creating the status quo around change management processes, and thereby taking up the authority to implement evidenced-based practice development, rather than waiting to be given the authority to lead change.

The ability to weave in and around, up and down the levels of the healthcare world, strategically implementing incremental change, may seem innocuous and somewhat simplistic, but over time may be far more powerful and sustainable than rapid reforms. These sorts of activities also in my experience have a profound and lasting effect on workforce and healthcare culture. I refer to my previous example of introducing adolescent healthcare perspectives and sustaining this change in the adult healthcare world. I have termed this role 'border consultancy', which is a component or activity of all nursing roles but most likely a key component of the nursing roles of clinical nurse consultants and nurse managers (the notion of 'border consultancy' is mentored by these roles in all other nursing positions. Border consultancy listens to and learns from patients and clinicians and then interprets and communicates up and down the organisation, on the edges and across diverse healthcare systems and into the policy context of health to find common ground and opportunities to influence responsive change. Its primary aim is to champion aspects of practice and/or policy reform and collaborate with stakeholders to bring about the required change.

A number of studies defining the components of clinical leadership have shown that the activities of a 'change agent', or what I have termed a 'border consultant', are integral to the outcome of practice development (Cain, 2005; Ham, 2003; West, Lyon, McBain, & Gass, 2004). A literature review was undertaken to refine understandings about the characteristics, qualities, and skills of practice developers. Despite the poor quality of information retrieved, it was possible to identify the following five descriptive categories that outlined the role of a practice developer:

1. Promotion and facilitation of change
2. Translation and communication
3. Education
4. Research
5. Quality audits (including the development of policies and guidelines).

(McCormack & Garbett, 2003)

I argue that these activities are critical elements in the clinical leadership required to bring about responsive change to optimise bio-psychosocial outcomes for young people with chronic illness. The activities of research, facilitating clinical practice development and modelling a healthcare culture that considers psychosocial outcomes for this group such as coping, strengthening resilience and normalising illness into an adolescent lifestyle, are implemented in the microsystem but seeded in the inter-linking activities of the exo and meso systems by 'border consultants'. The culture laid down in the microsystem is further nurtured and weaved by interlinking effects of clinical leadership activities in the exo and meso systems using the skill of border consultancy. The next step for clinical leaders is to link this work with the world largely external to nursing or higher levels of the healthcare world. This linking will require a different type of leadership and leadership activities.

The Macrosystem and Clinical Nursing Leadership in Policy and Healthcare Reform

The macrosystem, in my conceptualisation of the healthcare world, is the policy context of healthcare or the opportune nexus between the clinical and policy contexts of the healthcare system. Clinical leaders and clinical leadership activities at this level need to link and collaborate with nurse leaders, consumer groups, professional organisations, and other healthcare leaders to bring the acumen of the clinical world to the context of policy and healthcare reform. My analysis of the macrosystem of the healthcare world in Chapter 6 has put forward a number of recommendations for policy and healthcare reform. The intention of these reforms is to improve the outcome of healthcare services for patients and families in their endeavours to optimise their own bio-psychosocial health outcomes. These recommendations included a model of care that would bring together primary and secondary healthcare services; enhanced nursing roles, such as case managers and entrepreneurs, within shared governance arrangements or leading organisations; and the enhancement of psychosocial components of treating teams. More specifically, hospital and community health services should incorporate health promotion, disease management, and psychosocial services into integrated care pathways. These types of healthcare pathways should have an emphasis on patients with chronic and complex illness. For any of these recommendations to progress, nurses from the clinical context to the policy context of the healthcare world will require new knowledge in not only policy development programs, but also political leadership skills.

The increasing numbers of chronically ill people will bring many challenges to nursing leadership but the notion of nurses well connected to consumer groups, already underway in many quarters, can richly inform and become highly influential in healthcare reform. This is not to say that policy reform, or at least influencing reform, is a panacea to the challenges of chronic illness healthcare or an easy task that can be achieved quickly. However, the political invisibility of nursing has long been recognised, whereas working together with health care consumers has the opportunity to place nurse leaders in a far more influential position in policy reform. Robinson (1991) identified the health policy and nursing practice void, specifically the inability of nursing to bring practice wisdom and clinical research evidence to the policy development arena (Robinson, 1991). The crisis looming in the healthcare world of how to sustain health services to the burgeoning numbers of chronically ill people is an opportunity for nurses to step forward with a leadership strategy for the profession and an action plan for health care reform.

Antrobus and Kitson believe that nursing is in a position to influence policy development from the practice world but the profession needs to prepare its leaders for the task (Antrobus & Kitson, 1999). In an analysis of nursing leadership skills, they interviewed 24 nurse leaders in the clinical and policy context to identify a skill set for the task of influencing policy development (Antrobus & Kitson, 1999). The skills identified by the nurses emphasised the ability to translate and interpret practice knowledge and values into the language of policy and politics or to become 'bi-cultural'. The ability to be 'bi-cultural' meant that nurse leaders could hold the values of nursing whilst recognising and influencing the values and ideology of the socio-political context of the policy world of health care (Antrobus & Kitson, 1999). For this approach to be successful, strong relationships and networks between patients, clinical leaders and healthcare leaders would be critical to position the acumen of nursing in a lobbying capacity.

The art of lobbying politicians and policy writers for specific reforms has not been a part of contemporary nursing leadership and therefore is not a strong skill for the profession. Leadership skills at this level of the healthcare world need to include skills in how to lead clinically and politically with the ability to alternate between practice and policy knowledge. The skills identified by the Royal College of Nursing leadership program as critical for effective political leadership included the following tasks:

1. Develop whole system thinking
2. Map a constituency
3. Identify stakeholders and map their issues in relation to the patient care issue
4. Construct different briefs for different stakeholders utilising evidence and clinical experience
5. Build networks and relationships to become an influential operator
6. Align coalitions
7. Evaluate and review strategies.

(Antrobus, 2003)

The process at this level is more about translating a patient need or a solution to a healthcare issue into a lobby group at a political level to inform policy reform which will then inform practice development reform (Antrobus, 2003).

The clinical world of nursing requires political awareness but, at the macro level or policy context of health care, political nursing leadership activities are essential. This leadership involves the following activities:

1. Influencing public policy with nursing evidence and experience – clinical leadership

2. Lobbying for nursing inclusion in health bills – political nursing leadership
3. Campaigning for a particular health issue - political nursing leadership
4. Influencing emerging health policy debates – clinical and political nursing leadership
5. Seizing the agenda in formulating policy – political nursing leadership
6. Interpreting the differences between policy and practice – clinical and political nursing leadership.

(Antrobus, 1998)

The political work of developing policy has not been a part of nursing education or professional development to any great degree; therefore, I have included some discussion from outside nursing to better understand this area of leadership. The concept of entrepreneurial policy development is rarely referred to in the nursing literature and yet clearly seems integral to political nursing leadership activities. Kingdon (2003) describes the work of policy entrepreneurs as 'organised anarchy' in an unpredictable and chaotic world of politics. Kingdon's landmark work establishing strategies for policy entrepreneurs is informative and detailed (Kingdon, 2003). Whilst acknowledging the years of work involved in developing understandings and education programs in entrepreneurial policy development, I will briefly outline some of the important points for nursing. The process involves establishing policy communities or aligned coalitions that work together, often from different organisations, to develop detailed and well-evidenced policy proposals. The policy entrepreneurs persistently look for 'windows of opportunity' for action. These windows emerge when policies are reviewed or, alternatively, a major incident demands immediate solution. Kingdon believes governments often paradoxically stumble into situations that require a decision and this is when policy entrepreneurs need to be ready for action. Policy entrepreneurs are at the ready with policy solutions (Kingdon, 2003). This work would easily fit with political nursing leadership skills and would ensure that connections between clinical and policy contexts of the healthcare world were made and sustained.

Clearly, entrepreneurial policy development is not a precise science but what Kingdon terms a policy primeval soup where ideas or proposals bump into each other and some simply 'die'. Kingdon believes separate streams of problems, solutions and politics converge – a process he calls coupling and this is where policy entrepreneurs learn how to pull the issues together when a window of opportunity is opened by a critical event with associated pressure for reform. Therefore, the proposals need to be prepared, ready, and waiting (Kingdon, 2003). The criteria for a proposal to survive, until the window of opportunity opens, are as follows: technical feasibility; the proposal holds the values of the policy community; the community need to anticipate the reception of the policy proposal in the wider political arena such as cost and public acceptance; and the reception and acquiescence of elected decision makers (Kingdon, 2003). A proposal that contains these elements is likely to survive until the window of opportunity opens and will have the best chance of being endorsed.

Clinical leadership and policy entrepreneurial activities are strongly related. Nurses will need skills to engage in policy formation and reform. Hughes believes these skills include tenacity; perseverance; dedication; vision; risk taking and high-level relationship management abilities (well connected and networked) (Hughes, 2003). In terms of vision, Hughes believes nursing needs to look beyond the clinical area and view the world of healthcare through a much broader lens, incorporating global health policy reform perspectives. The profession of nursing will also need to identify these qualities in nurses and mentor skilled nurses to strengthen entrepreneurial development skills (Hughes, 2003).

In the chronic illness healthcare world, nurses can bring about and sustain a vision of young people with the best possible psychosocial status despite the presence of chronic illness. A model of care should have the capacity to address the psychosocial as well as the physical health problems associated with chronic illnesses. The current era of crisis and demand for responsive healthcare reform to appropriately care for the increasing numbers of chronically ill people should be a major nursing concern. The nursing profession can bring policy solutions to the political decision-making tables rather than concerns about the inadequacy of current models of care to optimise outcomes for this group. Hughes acknowledges that a significant level of tenacious risk taking is required to challenge the status quo in health policy formulation and reform (Hughes, 2003).

Policy development is a critical component of nursing practice. Patients need nurses to become involved in policy development to ensure reforms actually mean effective changes to models of care and clinical practice that are effective for them (Hughes, 2003). From Hughes' viewpoint, the acumen of nursing needs not only to drive entrepreneurial policy activities within the organisation where they practise but also at both state and national levels of the healthcare policy world. Nursing can and should set the agenda for healthcare policy and build coalitions of support to drive policy reforms within and outside nursing. Hughes' vision of a nursing role in policy formulation involves forming policy interest groups within nursing and building policy coalitions including nursing. These groups, utilising leadership and entrepreneurial activities, would collaborate to find solutions to tough issues such as responsive policy to optimise outcomes for people with chronic illness and mental health problems (Hughes, 2003). Hughes warns nurses to be very clear about what reform is required and what purpose the change plays in patient outcomes (Hughes, 2003).

Antrobus strongly encourages the nursing profession to include the political context in all nursing education and leadership activities (Antrobus, 2003). Further, nursing education programs will value-add education with a placement in policy development areas within government to enable nurses to understand the pathway that negotiates different value systems, within the clinical and political contexts of healthcare, to facilitate and bring healthy solutions to policy issues (Antrobus, 2003). This experience will help nurses to see how the work at the bedside connects to clinical and political leadership activities and opportunities to influence policy directions that shape clinical services, nursing practice and thereby patient outcomes.

The expansion and implementation of clinical and political leadership skills through the healthcare world will improve the influential capacity of nursing, and hopefully transform the public perception of nurses, as well as encourage them to take up positions and view themselves as healthcare leaders. The acumen of nurses as healthcare leaders, whether working at the bedside or at higher levels of the system with clinical, strategic, policy and political skills, will prepare the profession for the challenges that lie ahead at a more global level.

The Chronosystem Level of the Healthcare World and Clinical Nursing Leadership Activities

In the discussion of the chronosystem level of the healthcare world in Chapter 5, I highlighted a number of global issues of major concern, which are driving rapid healthcare reformations in many countries. These global drivers of change have included the following: the increasing numbers of ageing chronically ill people; the escalating costs of medical science and associated chronic illness healthcare interventions, the emerging ethical dilemmas regarding how to maintain equal access and distribute healthcare resources across multiple illness categories; the increasing mixed funding arrangements emerging in public healthcare with many services more available in the private sector; the commercialisation of health care in global financial markets and the workforce shortages across medicine and nursing. At the chronosystem level of the healthcare world, a global lens or a global view of the healthcare world is required. This way of viewing the healthcare world will encourage nurses to become more aware of global drivers of healthcare reform and the need to anticipate and plan for the impact of change on the Australian healthcare system.

The nursing profession in Australia is part of a global nursing body leading healthcare reform in countries around the world rather than from the traditional standpoint of the hospital or the state where they practice. The participants of a recent Global Nursing Partnership Conference were surveyed in order to understand the impact of the global nursing meeting on them as nurse leaders (Swenson, Salmon, Wold, & Sibley, 2005). The survey responses of 61 nurse leaders overwhelmingly agreed that meeting collaboratively to examine nursing workforce issues and trends, to develop country-specific nursing action plans, and to establish international partnerships will build a strong global nursing community (Swenson et al., 2005). Traditionally, international conferences and the nursing literature have brought nurses together at a global level. However, global partnerships developing action plans for global healthcare concerns will be a stronger platform for nursing leadership and an influential nursing discourse. The nursing profession itself is already a global and transitory workforce enhancing opportunities for a global profession and informed collegiate.

The movement of nurses around the world and across cultures raises the need to better understand cultural transition and the impact on health not only for individuals but also health services. Acculturalisation is emerging as another vital area of learning for nurses, not only as a professional issue but also for the welfare of patients. The global concerns for effective healthcare responses to major terrorist related disasters, pandemics such as avian flu, and the increasing numbers of aged chronically ill people of diverse cultures will continue to challenge the nursing profession to rethink the traditional provincial type of nursing education, leadership activities, research agendas and clinical practice. There is a growing demand from nurses around the world for a more global healthcare approach to nursing education (Pearson & Peels, 2001). This is particularly so, as nurses travel and work around the world, as well as the situation developing from increasing numbers of people from diverse cultures migrating or seeking refuge in foreign countries. The range of chronic illness and psychosocial concerns will vary, necessitating diverse and flexible assessment tools and interventions.

The context of care is also changing around the world with many hospitals admitting only the sickest of the elderly and the chronically ill with a greater demand on community and self care (Pearson & Peels, 2001). The escalating cost of healthcare is also placing pressure on public services to accept private funding to continue to offer a full range of services and risking access to services for many people, particularly those less able to afford healthcare services. Pearson and Peels (2001) argue that, if nursing is about assisting communities to reach their goals despite illness, the profession needs an awareness of the changing global healthcare world and to prepare nurses to practise in a complex and changing global healthcare system. The International Council of Nurses (ICN) also has raised concerns that healthcare systems lack plans for managing chronic illness at a global level (Burman et al., 2003). ICN also considers that current systems of healthcare management of chronic illness simply treat symptoms, resulting in fragmented services, inefficiency, and the exclusion of the patient in the healthcare planning and interventions. The impact of global drivers of change is already emerging in the chronic illness healthcare world in Australia emphasising the urgent need for a skilled nursing leadership to achieve sustainable reform. The full bearing of many global issues for healthcare has yet to fully impact on the Australian healthcare system. However, there are strong messages for nursing to think globally, anticipate the impact of global drivers of healthcare reform, and act locally.

Conclusion

In this chapter, I have brought together and discussed clinical nursing leadership in terms of definition, skills, attributes, and activities. I have also discussed specific and achievable leadership strategies and activities at each level of the healthcare system using EST from the perspective, experience, and position of a clinical nurse caring for young people with chronic illness.

I have argued that the values and activities of leadership should be the essence of all nursing roles, rather than set apart in specific roles away from the bedside or exclusively at higher levels of the healthcare world or isolated in the clinical context of care. I have laid out potentially achievable strategies for a clinical nurse to work towards at each level of the healthcare world to effectively participate in policy development and healthcare reform. These suggestions may appear simplistic if viewed from a different perspective or a different position within the healthcare world. I emphasise that this work is grounded in the perspectives of a clinical nurse looking toward the policy world and what is required to find a way forward to influence change. In this chapter, I have presented these strategies from this perspective and scope of experience to help a clinical nurse to utilise nursing practice knowledge to influence policy reform, and thereby the face of healthcare at the ward level. In the following chapter, I bring together the major discussions and findings of the work throughout my thesis and the ways in which nursing leadership, knowledge, and practice development activities can influence responsive policy development and healthcare reform.

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Chapter 10

Nursing Practice Scholarship and Clinical Nursing: A way forward to meet the challenges ahead

Introduction

Throughout this thesis I have viewed the healthcare world from the perspective of a clinical nurse caring for young people with chronic illness in an adult hospital. From this viewpoint I have seen many groups involved in government initiatives work with objectives to improve healthcare management of the chronically ill, yet the difficulties for young people with chronic illness and the face of healthcare at the ward and community health service level have remained the same. As a clinical nurse, I have looked to the policy-making world of health care for a way forward to sustain the practice development being achieved at the ward level to improve the management of psychosocial health problems emerging within the physical health presentation of chronic illness. The psychosocial struggles experienced by these young people, frequently associated with adolescent development, often confuse and at times confound the objectives of the largely medical model of health care, particularly in the adult hospital context of care. My aim this thesis has been threefold. Firstly, I wished to research the struggles and difficulties experienced by young people with chronic illness as a platform for the work of the thesis, secondly (utilising EST and Erikson's theory of psychosocial development) to extend knowledge about the psychosocial development of young people with chronic illness and to recommend responsive nursing interventions. Finally, I wished to explore and lay out potentially achievable leadership strategies for clinical nurses to bring this knowledge to influence policy reform. What I have not tried to do is present a detailed analysis of nursing leadership and power issues within the healthcare world beyond the scope and experience of a clinical nurse; rather I have chosen to focus on what a clinical nurse could potentially achieve by developing skills in leadership and policy development.

The aims of my work would require a change in thinking about health outcomes for young people with chronic illness to include more psychosocial achievements and to enable clinical nursing, using clinical leadership skills and activities, to participate effectively in practice development, clinical service model re-design and policy development and reform. Early in my studies, I realised that to achieve effective and sustainable practice development two things needed to occur. First, a fundamental shift in thinking about chronic illness is required, moving from the position of managing illness and disability to optimising psychosocial wellness despite chronic illness. Second, I needed to raise awareness that clinical nursing leadership activities are potentially powerful mediators in healthcare and policy reform, and to provide strategies and examples on how to go about clinical leadership.

This thesis, therefore, contributes in two major ways. The thesis extends knowledge of the psychosocial development of young people with chronic illness and the important role of psychosocial mastery in the development of coping skills to live well with chronic illness. Further, the thesis sets out potentially achievable strategies for clinical nurses to bring practice scholarship to inform clinical leadership activities at each level of my framework of the healthcare world, in order to influence and participate in healthcare and policy reform. Within this chapter, I bring together my main findings and recommendations made throughout my thesis.

Review of Practice Concerns and Ways Forward to Optimise Psychosocial Health Outcomes

The work of this thesis emerged out of my clinical practice concerns for chronically ill young people in an adult hospital. The young people had illnesses such as cancer, cystic fibrosis, and major organ failure. The review of these practice concerns, which led to my doctoral work, included the following: frequent re-admissions to hospital with exacerbations of illness, problematic treatment adherence, depression, loneliness, persisting anxiety, suicidal thinking and behaviour, sexuality concerns, relationship problems, substance abuse, poor literacy, underemployment (despite the availability of suitable employment) and many socio-economic struggles.

I have speculated that these problems may be partly premorbid and that some young people have fewer coping resources to deal with adversity more generally in their lives. The emergence, or presence, of chronic illness during the developmental period of adolescence most likely further challenges limited, underdeveloped or yet to be developed coping resources. Among the young people, I identified a subgroup experiencing poorer psychosocial health and greater struggles with treatment adherence compared to their peers with similar levels of illness and disability. My concerns were principally about the psychosocial difficulties experienced by some young people and, particularly, survivors of chronic illness and cancer. I was also concerned with the seeming invisibility of this group within the adult healthcare world and the failure to recognise the struggles involved in growing up as a young person with a chronic illness.

Summarising The Literature

A review of the literature in Chapter 2, and further literature as it became relevant throughout this thesis, has revealed that a more responsive healthcare model is required to address the psychosocial and developmental needs of young people with chronic illness, to ensure that survival from illness leads to living a worthwhile life. Advances in medical science and healthcare technology have largely shaped contemporary healthcare resulting in a highly technical medical and nursing care that increases the likelihood that young people will survive diseases of childhood that were once considered terminal. The contemporary health care needs of young people with chronic illness have been demonstrated to frequently cut across medical and psychosocial domains. However, the traditional medical model of care, a strong mediator of healthcare in adult hospitals, makes it difficult to systematically identify or respond to the increasing psychosocial - and, for some, psychiatric components - of their illness and disabilities. The medical model with its focus on the physical symptoms of illness, and the markers of both therapeutic and adverse effects of treatment, may overlook or not recognise the struggles and, at times, the distress experienced by young people trying to adjust to living with chronic illness and develop as a young person.

In the literature review I further identified that the clinical assessment of psychosocial status is problematic and difficult to achieve without the use of a suitably developed psychosocial assessment tool and that there are difficulties associated with the incorporation of psychosocial assessment into routine healthcare. Psychiatric assessment tools used commonly to identify psychiatric pathology are not generally sensitive to the markers of early distress or psychosocial acuities common to young people struggling with chronic illness. Early indicators of distress and mental illness present differently at each developmental level; and issues that cause distress among young people with chronic illness can be part of the healthy developmental experiences of adolescence. An appropriately sensitive psychosocial assessment tool is required to identify young people experiencing difficulties coping with their illness, particularly during adolescence. I have come to the position that the increasing rate of psychosocial and psychiatric problems among chronically ill young people may well be, in part, an indirect result of an unprepared healthcare system for this relatively new group of patients.

As discussed throughout this thesis the literature has provided some evidence, although weak, that most children, adolescents, and families cope and adjust well to living with chronic illness (Leblanc, Goldsmith, & Patel, 2003; Patterson et al., 1997; Stuber, 1996). However, there is a small amount of evidence, although again weak, of a subgroup of young people expressing more difficulty than others in adapting to chronic illness (Burke & Elliott, 1999; Goldston et al., 1997; Smemesh et al., 2000; Stuber et al., 1997). Studies exploring the psychosocial health of young people with chronic illness in an adult hospital have been difficult to find. What is striking is the lack of discussion in the nursing literature about the increasing psychosocial acuity of some young people with chronic illness, and the difficulties in caring for this patient group that were clearly evident in my clinical milieu within a large and leading adult teaching hospital. In recognition of this gap in the literature, I decided that the research component of my thesis would explore the psychosocial health of young people in an adult hospital and in order to understand more about the difficulties that this group experience with treatment adherence and living with chronic illness more generally as a young person.

Summarising The Empirical Study

At the conclusion of Chapter 2, it was clear that a great deal of concern about the psychosocial struggles of the chronically ill and my clinical experience (discussed in chapter 1) highlighted the difficulties managing young people with chronic illness, particularly in regard to treatment adherence. However, little was known about the psychosocial health of young people with chronic illness in an adult hospital, and even less about what responsive frameworks for nursing practice and/or interdisciplinary interventions would need to consider. Therefore, in Chapter 3 I reported on a quantitative and qualitative research study I undertook to understand more about the psychosocial functioning of young people with chronic illness in an adult hospital context, to determine whether there is any relationship with treatment adherence, as well as specific difficulties with treatment adherence and living with a chronic illness as a young person. The research questions were: -

1. Is the psychosocial health of young people with chronic illness different from those without chronic illness?
2. What problems do young people with chronic illness have with treatment adherence?
3. What concerns do young people with chronic illness have with other aspects of their lives?

4. Is there a relationship between psychosocial functioning and difficulties with treatment adherence?

The major findings from this study suggested that young people with chronic illness most likely have an increased vulnerability to poorer psychosocial functioning compared to their peers without chronic illness. The findings of the study also showed that young people with poorer psychosocial health also had difficulties with treatment adherence, particularly in the young adult group. Interestingly, some young people in the study who identified multiple psychosocial concerns seemingly had few difficulties with treatment adherence. The study findings highlighted the fact that utilising better treatment adherence as an indicator of good psychosocial health may be misleading.

The study findings added to my argument that the incorporation of psychosocial assessment into routine healthcare interventions is vital to identify young people struggling with not only treatment adherence but also to adjusting to life with chronic illness. Further, that appropriately sensitive screening tools used by nurses potentially can identify young people struggling with their illness and its treatment, enabling early referral to therapeutic services. At the conclusion of Chapter 3, I recognised that further exploration and study of the psychosocial health of young people with chronic illness in isolation to the healthcare world would not achieve my aims of building psychosocial assessment into routine health care; bringing recognition of psychosocial development in healthcare interventions; and developing a more responsive model of care to the psychosocial needs of young people with chronic illness that could then inform policy development. What was required was not only a greater understanding of the psychosocial health of this group, but also a thorough analysis of the chronic illness healthcare world and the role, or potential role, of the clinical nurse in bringing about change.

The Theoretical Analysis of the Healthcare World

The sheer size of the healthcare world of the chronically ill cannot be underestimated and has been almost overwhelming to understand. I decided to divide the area of study into two worlds: an external world and internal world; the external world to contain the healthcare system and nursing practice scholarship; the internal world to contain young people with chronic illness during adolescence, and their interplay with nursing practice. These two worlds meet at the interface of patient care or at a nexus where opportunities exist to optimise developmental experiences, coping skills, and a more responsive model of care. I have argued that clinical nursing leadership, in terms of new knowledge and practice development, is the interlinking factor that can bring about responsive change and better bio-psychosocial outcomes for young people with chronic illness.

Given the complexities of this area, I needed a framework to organise the external and internal worlds of young people with chronic illness. I used Bronfenbrenner's EST to construct and organise the external healthcare world. The framework organises the healthcare system into a series of five systems or five levels, each holding an environmental healthcare context. These five environmental contexts contain factors that interact to facilitate, impose, or prevent change up and down the healthcare system from the level of government to the point of care. The highest levels of the framework are associated with the global chronic illness healthcare issues that drive reforms within the NSW healthcare system and, subsequently, have significant ramifications for the professional world of nurses and the day-to-day lives of the chronically ill. The lower or more local levels of the framework contain the young person and conceptualise the point of patient care, nursing practice and the internal world of young people with chronic illness. This way of organising the healthcare world made it much easier for me to analyse the healthcare world, extend knowledge about the internal world of young people during adolescence and discuss strategies for the clinical nurses to bring knowledge and practice experience to participate in healthcare reform.

Ecological systems theory proved to be an effective framework to organise and analyse the complexity of the healthcare world, specifically its argument that bi-directional influences can impact on the lives of individuals toward a positive or negative outcome. However, like all theories it has a few weaknesses, which affect the objectives of my work. Ecological systems theory provides a strong theoretical argument that individuals develop in response to interactions between socio-cultural factors in the environment (Bronfenbrenner & Morris, 1997). Bronfenbrenner's ecological framework is particularly appropriate to analyse the healthcare world of young people with chronic illness as it provides a systematic approach to examine the contextual factors that impact on the young person. This includes factors that interact without the presence of the young person, but indirectly affect the developmental outcome for the young person. At the microsystem level, the phenomenon under examination was the psychosocial development of the young person and the interaction with nursing practice, resulting in a development outcome for the chronically ill young person.

This examination required more developmental information across a life span of staged developmental vulnerabilities and achievements than was available within Bronfenbrenner's definition of the microsystem. What I required was sufficient detail about what was occurring in the young person's internal world to then develop a critique of nursing practice and to make recommendations for nursing practice development. These findings then informed further analysis and discussion at the exo and meso system levels. At this point in the discussion, I recognised that the phenomena of how young people cope and adapt to chronic illness required a thorough analysis to further inform not only nursing practice development but also policy development at the macrosystem level of the framework. Therefore, I decided to complement ecological systems theory with Erikson's theory of psychosocial development from infancy to young adulthood to provide the level of detail I required to meet the objectives of my work.

What I have offered throughout my thesis are ways for clinical nurses to explore nursing practice problems by undertaking a thorough analysis of contextual factors, internal and external to young people with chronic illness and the professional world of nursing, within a broader context of a vast healthcare world. I have used both theory and the literature to create new knowledge and strategies to inform practice development, clinical leadership activities for clinical nurses and ways to use this knowledge to influence policy reform.

In Summary: Major findings and recommendations for each level of the healthcare world

I now bring together the findings and recommendations of the theoretical investigative component in the same order as the chapters of my thesis. The main tenet of my conceptualisation of EST is that environmental bi-directional factors/influences impact on the lives of individuals to bring about change. I begin with the chronosystem level, the highest level of the framework, and the most distal system to the young person with chronic illness. This environment has a strong influence on the NSW healthcare system and, largely impacts upon the efficacy of clinical nursing practice in dealing with young people with chronic illness.

Chronosystem: The global healthcare world

Major Findings

Conceptualising the chronosystem drivers of change in the healthcare world was by far the most difficult of the five levels of this model. These global drivers of change are identified in Chapter 5 and include the following: the increasing numbers of ageing chronically ill people; the escalating costs of medical science and associated chronic illness healthcare interventions; the emerging ethical dilemmas about how to maintain equal access to and distribution of healthcare resources across multiple illness categories; the increasing mixed funding arrangements emerging in public healthcare with many services more available in the private sector; the commercialisation of healthcare in global financial markets; and the workforce shortages across medicine and nursing. These issues have created an impetus for major reforms: specifically, for the ways in which healthcare is organised and funded in many countries around the world.

The escalating cost of healthcare and the workforce shortages are becoming major concerns for all countries resulting in a re-examination of the efficacy and efficiency of healthcare systems and, in particular, the cost and payment of services. In some countries, nursing, in response to the introduction of changing healthcare arrangements, has developed innovative and competitive practice models in the market place of managed care. These new models of care, some with nursing leadership, have the capacity to identify and resource the psychosocial and developmental needs of patients (Clendon, 2005). Innovative models, such as nurse led managed care services, nurse clinics and nurses in shared care arrangements with primary care providers, offer exciting opportunities for nurses despite moves away from publicly funded healthcare systems (Clendon, 2005; Storfjell et al., 1997; Whitecross, 1999).

Ethical issues emerge for specific patient groups as healthcare services move toward fee-for-service and mixed payer models. The response by many governments, faced with the increasing burden of chronic illness and unsustainable cost of healthcare, has been the introduction of capitated funding healthcare systems. The most vulnerable groups within these systems of healthcare are the elderly and children of poor families affected by chronic illness. These groups are less able to afford the health insurance premiums required by such organisations. This situation can easily result in subgroups of the population with less access to health care and, consequently, poorer health status. Australia may see managed care systems transpire in the near future, and some commentators argue that the hallmarks are already emerging in NSW (Heslop & Peterson, 2003; Marcus, 2000). The literature generally, and specifically the nursing literature, is surprisingly quiet about these issues that are already apparent in Australia. As nurses we have a responsibility to recognise these issues and advocate appropriately for the chronically ill, particularly those less able to afford healthcare insurance.

Innovative practice models about critical junctures of the healthcare pathways hold opportunities to improve the continuity, efficiency, and effectiveness of care. The transition of patients from the hospital system into the community is the most problematic and often the least resourced of current models of care (Naylor et al., 1999). Nurse case managers and discharge planners linking hospital and primary health care can work in partnership with patients to coordinate and plan chronic illness care across contexts of care (Naylor et al., 1999). Nurses working in shared care models as equal partners with doctors can work in collaboration with hospital services. This collaboration can became a powerful clinical coordination of care providing outcome focused case planning, direct patient care, and opportunities to monitor psychosocial health and functioning. Similar models of care have been able to reduce inpatient length of stays, lower readmission rates and make improvements to the bio-psychosocial health status of patients (Naylor et al., 1999; Schifalacqua et al., 2000). Models of care that improve the efficiency and efficacy of health care will be sustainable regardless of how the healthcare system is funded.

For nurses to take on leadership positions new skills will be required in healthcare business management, ethics, and policy development. This will almost certainly mean relinquishing some more traditional nursing roles and taking up new responsibilities. With these skills, nursing will then be able to step forward and take up positions within the governance and leadership of organisations, not only as clinical experts but also with the acumen of the ethical and fiscal business of health care. The ability to understand the global healthcare world and interpret changing trends will equip nurses to participate fully in the healthcare future of NSW.

Recommendations for Clinical Nurses

1. Consider opportunities to take up healthcare leadership positions within new healthcare models

2. Clinical nurses to consider a global view of health care and policy development, nursing research directions and international practice development activities to ensure change is anticipated and shaped effectively for specific patient groups

3. As healthcare systems and service models change, advocacy is required by clinical nurses to recognise the specific vulnerabilities of particular patient groups such as poorer families affected by chronic illness and disabilities

4. Clinical nurse leaders to enhance skills in healthcare business, ethics and policy development

The Macrosystem: The NSW healthcare system

Major Findings

The bi-directional nature of EST's chronosystem brings change and opportunities for reform at the macrosystem level of the healthcare world. The macrosystem level of my conceptual framework is presented in Chapter 6. The macrosystem contains the NSW healthcare system and, in particular, the resources, threats and opportunities for an effective healthcare system for young people with chronic illness. I have explored and critiqued the major policy directions currently driving healthcare reform in NSW as they relate to chronic illness health care. I have identified opportunities for nursing to put forward models of care and nursing roles specifically focused on the biological as well as the psychosocial healthcare needs of chronically people. With enhanced skills, nursing can address many of the current issues by considering outcome-focused clinically effective, ethically sensitive, fiscally rational, and sustainable models of care. In this section, I briefly review the current challenges and policy directions in NSW and my recommendations for nursing.

The current challenges facing the NSW healthcare system include long waiting lists for elective surgery; overloaded emergency departments; long hospital stays; frequent urgent readmissions of chronically ill patients; the spiralling cost of chronic illness care and significant workforce issues (New South Wales Health Council, 2000). Better health outcomes for the chronically ill are increasingly related to the financial capacity of the patient, rather than to the actual complexity and severity of the illness per se (Wilson, 2005). Australian healthcare consumers will ultimately confront the issues of how to maintain a 'free' (publicly funded) yet equitable and sustainable healthcare system. However, these issues are rarely discussed in the nursing literature despite the rapidly advancing private healthcare sector. Callahan (1997) holds the view that, if patients continue to demand free healthcare for all, with a cure at all costs perspective, rather than a chronic illness outcome for some, the healthcare systems, particularly public funded systems, will collapse (Callahan, 1997). The greatest risk to patients is that the situation will emerge where only those who can afford health care will be able to sustain good health and a higher level of bio-psychosocial functioning despite chronic illness. The irony is that the situation will reduce access to people who cannot afford to pay for health care, resulting in worsening health states, increasing lengths of hospital stay and a more expensive healthcare systems in the long term.

A great deal of policy and service reform is underway in NSW. However, there are issues that historically have not been addressed or are making very slow progress to resolution. Unless these issues are resolved the fate of new projects and appropriate reforms are compromised. These issues include:

- Rapidly increasing numbers of patients with complex chronic illness
- The recruitment and retention of staff and the persistent low morale of staff
- Outdated health worker skills sets and roles
- Increasing disconnects i.e. fragmentation between services – hospital and primary care services
- High turnover and insufficient numbers of general practitioners
- Unrealistic time frames imposed by policy reforms and new programs
- Problems with data collection, data access and management infrastructure
- Cultural resistance in changing from existing models of care
- Lack of local ownership of the new programs
- Limited resources to implement the complex and chronic illness programs
- The need for chronic illness services being greater than anticipated
- The training needs of staff greater than available resources
- The needs of the chronically ill cutting across historically divided service domains – physical and mental health services
- Frequent readmission of chronically ill patients to hospitals for exacerbations often related to or including psychosocial concerns

- Inadequate community resources for the diverse needs of the chronically ill to remain well with fewer hospital admissions
- Increasing costs of chronic illness care without corresponding improvements in health outcomes.

In Chapter 6, I argued that, unless efforts are made to resolve these issues which are beyond the scope of my work, the success of all healthcare reforms will be compromised. I identified and explored a number of new models of care and roles for nurses, placing nursing in leadership roles to address some of the issues and challenges facing the NSW healthcare system. The discussion in chapter 6 unfolded to conclude that different types of nursing leadership skills were required at different levels of the healthcare world for clinical nurses to participate in healthcare reform. The pertinence of new nursing leadership skills increased in gravity as I worked through my thesis. Therefore, I decided to examine the area more closely and make specific recommendations in Chapter 9.

Recommendations for Clinical Nurses

1. In the current situation of healthcare reform nurses, can put forward new models of care and innovate outcome-focused practice models to improve the utility and efficacy of healthcare for the chronically ill.

2. An advocacy role is required by nursing to foresee and present solutions to avoid the inequities in access to health care and the situation of unaffordable health care for some families affected by chronic illness and disability.

3. Clinical nurses need to assume a more political view of health care and take an active role within healthcare organisations from the position of patient advocate to ensure reforms are not only effective and but also have genuine utility in the day-to-day lives of the chronically ill and their families.

The Exo and Meso Systems: Nursing scholarship linking the macrosystem to the microsystem

Major Findings

The exo and meso levels of my conceptual framework are the interlinking systems, influencing up to the macrosystem and down to the microsystem. I have theoretically represented the exo and meso system levels of my conceptual framework as hospital service models and the action role of nursing scholarship informing both policy reform at the macrosystem and, the interplay and outcome of nursing practice with the internal world of the young person with chronic illness at the microsystem level. The young person is indirectly influenced by the acumen of nursing scholarship with the exo system and more directly by the aims of nursing scholarship to improve coping skill development and adaptation to chronic illness in the meso system. My analysis has identified the interlinking role of nursing scholarship, both as clinician and operating within interdisciplinary teams, to be a powerful mediator in healthcare reform can potentially optimise the psychosocial outcomes for young people with chronic illness.

I identified from my review of the nursing chronic illness literature, that there were few articles that discuss the psychosocial development of chronically ill young people, in particular, frameworks for nursing practice, that optimise coping for this group in an adult hospitals. This is not to say that there is not literature available that discusses coping among the chronically ill, but a perspective that a deeper understanding of coping skill development was required for adult clinical nurses, caring for young people, to draw upon. This work will inform the development of frameworks for psychosocial nursing and interdisciplinary practice. The following seven components of coping probably interrelate in some way to enable the development of better coping skills for young people with chronic illness:

1. Psychosocial developmental mastery
2. A sense of coherence
3. The trait of resilience
4. Locus of control
5. The utility of social and familial support
6. The strategy of normalising illness
7. The role of hope in adversity

This schema or framework of what is required for young people to develop coping skills, which I have identified in Chapter 7, will assist in the development of responsive nursing practice and interdisciplinary interventions to facilitate coping skill development. It could also reasonably apply that the absence or the ineffective development of these seven components of coping could impair or imbed the young person's ability to cope with the impact of chronic illness, particularly during the development period of adolescence. This hypothesis challenges existing notions of generic 'nursing support' intended to assist people to cope with illness related adversity. The notion of general nursing support arguably is becoming part of nursing rhetoric. Nursing support has been poorly defined throughout the literature with little definitive explanation of how it is operationalised in nursing practice and how to measure its affect in patient outcomes (Kyngas & Rissanen, 2001; Spitzer et al., 1995; Trask et al., 2003).

Some or all of these components of coping are likely to be the result of psychosocial developmental achievements. The next step will be to understand how to develop ways of delivering nursing interventions that enhance these factors for the young person and their family. The research I propose will develop a conceptual model of coping to underpin specific nursing practice development and the interdisciplinary interventions needed to optimise psychosocial outcomes.

Recommendations for Clinical Nurses

1. A greater understanding of how young people, cared for in adult hospitals, cope with chronic illness and the facilitative role of nursing practice in coping skill development.
2. The consideration of a schema to inform interactions with, and interventions for young people with chronic illness: specifically, about what is required to cope with the impact of chronic illness during the psychosocial developmental period of chronic illness.
3. Increased recognition the utilization of nursing knowledge as both a tool and an action within the governance levels of healthcare services to inform the development of outcome-focused policy, models of care and nursing/interdisciplinary interventions.

The Microsystem: Nursing practice and the internal world of young people with chronic illness

Major Findings

I have argued throughout my thesis that clinical nursing leadership and practice scholarship and practice development at the clinical level, as well as acting and advocating from the clinical level with other levels of the healthcare world, are potentially powerful mediators in the psychosocial outcome of young people with chronic illness. I have also argued that the bi-directional influencing mechanism of EST can facilitate these actions. In Chapter 7, I identified that psychosocial development mastery is a vital component of, and mostly likely acts with, other identified components of the coping process. I also put forward in Chapter 7 that the role of psychosocial developmental mastery can be facilitated by specific components of well-constructed models of care (assessment, monitoring and appropriate referral of psychosocial health problems). However, as previously stated, little information is available to clinical nurses in the adult context of chronic illness health care to assist in the development of responsive models of care and frameworks for practice. I decided that to analyse and discuss effective nursing practice, and the role that nursing practice might play in interdisciplinary interventions to facilitate stage-related psychosocial development and developmental mastery I would need to cross reference the discussion with a normal psychosocial trajectory and utilise case studies.

In Chapter 8, I presented a normal psychosocial developmental trajectory as well as case studies to demonstrate both the impact of chronic illness on psychosocial development and ways to facilitate developmental mastery or at least maintain the level of previous mastery. Chapter 8 presents several case examples to better understand the impact of chronic illness on psychosocial development at each stage, also the facilitative role of nursing practice, as well as some broader discussion to better understand specific struggles for young people with cancer attempting to re-adjust to living a normal life during remission. I have varied this discussion to ensure the recognition and consideration of a range of psychosocial consequences emerging from a range of disease outcomes.

I included case presentations in Chapter 8 that related to the presence of chronic illness since birth, the specific issues for young people with disabilities, the role of parents and the experience for young people of receiving a diagnosis of a chronic illness. I also included discussion and case examples of the situation where diagnosis of a chronic illness comes during adolescence, bringing its own special challenges. There is the threat of death for these young people during the acute phase, the threat of relapse during remission and the prospect of living with lifetime complications and/or disabilities because of treatment. I have also included in my discussion diseases that can be completely managed, such as congenital cardiac diseases or those that have required organ transplant. Treatment for these diseases can ameliorate symptoms and complications almost to a point of complete physical wellness, but the management is so disruptive to psychosocial development and an adolescent lifestyle that specific frameworks for responsive nursing practice are required to consider psychosocial outcomes for this group if they are to move on with their lives following 'cure'. I included these specific cases, as these are the most common types of patients seen in the care of young people with chronic illness. The cases I selected represent many of the concerning issues for health care and are the most difficult for nurses when caring for this patient group and their families.

The discussion and practice frameworks for clinical nurses caring for young people in adults hospitals presented in Chapter 8 lay at the centre of my doctoral work. I would like to continue this work as postdoctoral research to develop an evidenced-based and appropriately sensitive psychosocial assessment tool. Such an instrument can provide information about the young person's level of psychosocial development and how they are coping with their illness. This information would be useful for care planning but also for the development of responsive policy reform and practice development at other levels of the healthcare world to optimise bio-psychosocial health outcomes for young people with chronic illness.

Recommendations for Clinical Nurses

1. Psychosocial assessment should be recognised as a key part of the routine clinical assessment of young people with chronic illnesses and those in remission from cancer.
2. A thorough understanding of psychosocial developmental theory and its application to nursing practice and interdisciplinary interventions is vital in chronic illness health care, particularly for young people in the adult hospital context of care.
3. To raise the awareness of, and consideration for, a range of consequences that result from different types of illnesses and treatment outcomes on physical status and the implications for psychosocial functioning and development. Specifically, there needs to be increased understanding about what sorts of interventions will be helpful for young people and families with different psychosocial needs.

Clinical Nursing Leadership: Key to responsive reform at each level of the healthcare world

Major of Findings

Throughout my thesis, I have researched and discussed the healthcare response to the specific needs of young people with chronic illness at each level of the healthcare world. I have made recommendations for nursing to participate more fully in healthcare reform, advocated the use of developmental theory and its application in nursing practice development and interdisciplinary interventions/activities at each level of my conceptual framework. At each stage of my thinking and writing, I have constantly returned to the same premise. For nursing to have a helpful and sustainable voice in healthcare reform, different types of leadership and leadership activities will be required at each level of the healthcare world.

In Chapter 9, I extended the use of the ecological systems theory framework to further explore what types of nursing leadership and what specific leadership skills, relevant to my field, are required at each level of the healthcare world. Given the importance of leadership to the actions and outcomes of nursing scholarship, at each level of the EST framework, I decided it necessary to deepen the analysis and discussion. I emphasised that my position in my research and in the development of ideas around leadership activities are from the perspective of, and operate from, the experience of a clinical nurse. I presented a number of ideas about leadership and identified a number of strategies in Chapter 9, which could be used by clinical nurses to influence healthcare policy reform and practice development from the clinical level of healthcare. I have deliberately focused on my professional area, the objectives of my work as a clinician, and of this thesis being of assistance to nursing practice development to optimise psychosocial health outcomes, alongside physical health outcomes, for young people with chronic illness and their families. I have argued that the values and activities of clinical leaders needed to influence policy reform and practice development should be part of the practice of all nurses, rather than set apart in specific nursing roles away from the bedside. Those leadership activities should not be held or implemented exclusively at higher levels of the healthcare world nor, on the other hand, remain isolated in the clinical context of care, carrying uncertain sustainability.

The higher levels of the healthcare world will require more entrepreneurial and business leadership skills while lower levels, closer to the patient, require clinical leadership skills and activities in order to influence teams in responsive practice development and policy reform. The next step will be to connect leaders and leadership activities at each level of the framework. This process could involve the establishment of policy and practice communities or aligned coalitions, which work together, often drawn from different organisations, to develop detailed and well-evidenced policy proposals to influence healthcare solutions for the future.

Recommendations for Clinical Nurses

1. There should be participation of clinical nurses in clinical leadership activities from the clinical level of healthcare in ways that can influence and enhance the acumen of nursing, and the role of nursing acumen, at all levels of the healthcare world.
2. Skill enhancement is needed for clinical nurses in healthcare policy development and political skills, for them to participate effectively in, and contribute to, policy research and reform.

Conclusion

In this doctoral thesis, I have undertaken a review of the literature; a quantitative and qualitative study; and a theoretical investigation of the healthcare world of young people with chronic illness. My position in my research has been that of a clinical nurse finding solutions for clinical problems emerging in the healthcare of young people with chronic illness. The objectives of my work have been to analyse clinical problems and to find practice solutions through an analysis of relevant literature and the application of theory, and recommendations are made for clinical nursing practice and clinical leadership activities.

The research context has been the psychosocial health and outcomes for young people with diseases such as cancer, cystic fibrosis, and organ transplant in a large adult teaching hospital. The research component of this thesis has generated some evidence that young people with chronic illness who have poorer psychosocial health also struggle with treatment adherence. The research findings also suggested that using treatment adherence as a marker of better adaptation to chronic illness and illness stability may be misleading and that a greater understanding of how young people cope and adapt to living with chronic illness and the implications of illness and treatment on psychosocial health is required. Notwithstanding the need for more research, I have argued that the development of psychosocial assessment tools screening for markers of psychosocial development master, levels of coping skills and indications of psychosocial distress is a better approach to understanding and optimising the bio-psychosocial health of this group.

I have established a deeper understanding of psychosocial development, the application of psychosocial theory to nursing/interdisciplinary interventions for chronically ill young people in the adult context of care. Following an analysis of the coping literature, with a particular emphasis on literature related to chronically ill young people and the identification of and development of coping skills, I have identified seven components of coping that I have termed the coping process. These factors are amenable to change and can be mediated by clinical nursing leadership activities in policy reform and practice development at multiple levels of the healthcare system. I have given a number of clinical examples to illustrate how psychosocial developmental theory can be applied to clinical nursing problems to establish responsive nursing frameworks in order to optimise the developmental experiences for young people with chronic illness.

As I have moved through my doctoral studies I have come to the conclusion that nursing leadership skills and activities, operating from the clinical world, can provide opportunities for nurses to participate in and inform effective policy development at higher levels of the healthcare world. The traditional nursing acumen of patient care and managing health service operations will continue to be important roles for nursing, but the role of clinical nurses as influential healthcare leaders will become more accepted in the politics of healthcare. Entrepreneurial policy reform activities which engage patients and clinicians will become a core activity for many clinical nurses to ensure policy reforms and practice development have utility in the day-to-day lives of the chronically ill and their families.

The Australian healthcare workforce has changed significantly over recent years and will need to continue to do so. The question remains whether nurses will lead some of this change that includes and affects the profession and vulnerable consumers. Nursing roles will need to change, with some components of practice undertaken by other types of personnel, and new roles will emerge with a different mix of responsibilities, skill sets, and educational needs.

There remains much work to be done to sustain the best possible healthcare system for chronically ill young people. Undoubtedly, advances in medical science will continue to change the implications of chronic illness in the day-to-day world of young people and the implications for psychosocial developmental outcome. The challenge for the future will be to ensure that the healthcare response is flexible and responsive to the specific needs of the chronically ill. My thesis will add to, and most importantly challenge, the existing body of knowledge and the role of clinical nursing leadership and practice in this field.

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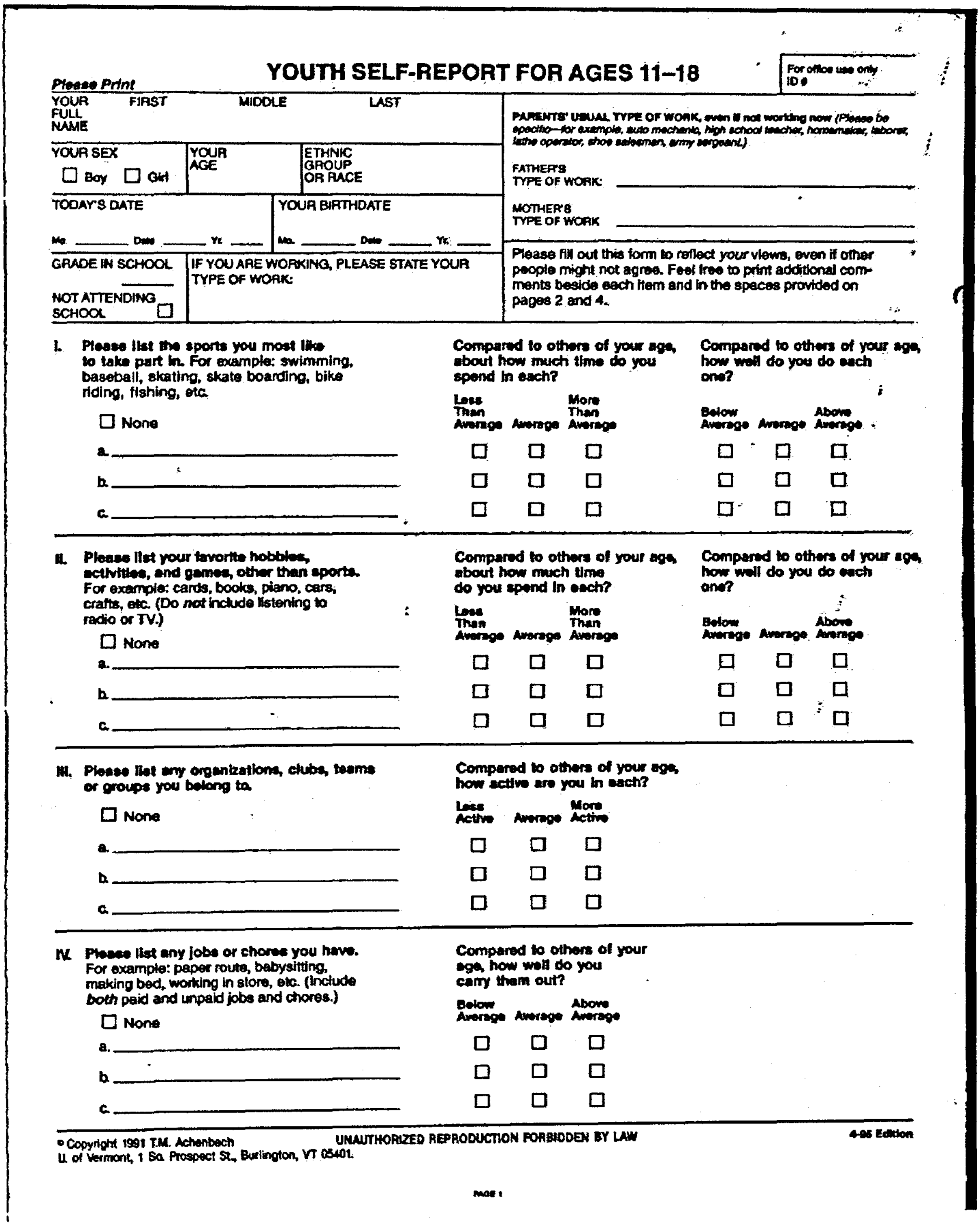
Appendix 1



Please Print

YOUTH SELF-REPORT FOR AGES 11–18

For office use only
ID #

YOUR FULL NAME FIRST MIDDLE LAST

YOUR SEX ☐ Boy ☐ Girl

YOUR AGE

ETHNIC GROUP OR RACE

TODAY'S DATE Mo. ______ Date ______ Yr. ______

YOUR BIRTHDATE Mo. ______ Date ______ Yr. ______

GRADE IN SCHOOL ______

NOT ATTENDING SCHOOL ☐

IF YOU ARE WORKING, PLEASE STATE YOUR TYPE OF WORK:

PARENTS' USUAL TYPE OF WORK, even if not working now *(Please be specific—for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK: ______________________

MOTHER'S TYPE OF WORK ______________________

Please fill out this form to reflect *your* views, even if other people might not agree. Feel free to print additional comments beside each item and in the spaces provided on pages 2 and 4.

I. Please list the sports you most like to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of your age, about how much time do you spend in each?			**Compared to others of your age, how well do you do each one?**		
	Less Than Average	**Average**	**More Than Average**	**Below Average**	**Average**	**Above Average**
a. ____________	☐	☐	☐	☐	☐	☐
b. ____________	☐	☐	☐	☐	☐	☐
c. ____________	☐	☐	☐	☐	☐	☐

II. Please list your favorite hobbies, activities, and games, other than sports. For example: cards, books, piano, cars, crafts, etc. (Do *not* include listening to radio or TV.)

☐ None

	Compared to others of your age, about how much time do you spend in each?			**Compared to others of your age, how well do you do each one?**		
	Less Than Average	**Average**	**More Than Average**	**Below Average**	**Average**	**Above Average**
a. ____________	☐	☐	☐	☐	☐	☐
b. ____________	☐	☐	☐	☐	☐	☐
c. ____________	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams or groups you belong to.

☐ None

	Compared to others of your age, how active are you in each?		
	Less Active	**Average**	**More Active**
a. ____________	☐	☐	☐
b. ____________	☐	☐	☐
c. ____________	☐	☐	☐

IV. Please list any jobs or chores you have. For example: paper route, babysitting, making bed, working in store, etc. (Include *both* paid and unpaid jobs and chores.)

☐ None

	Compared to others of your age, how well do you carry them out?		
	Below Average	**Average**	**Above Average**
a. ____________	☐	☐	☐
b. ____________	☐	☐	☐
c. ____________	☐	☐	☐

4-95 Edition

PAGE 1

Please Print

V. 1. About how many close friends do you have? ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more
(Do *not* include brothers & sisters)

2. About how many times a week do you do things with any friends outside of regular school hours?
(Do *not* include brothers & sisters) ☐ less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to others of your age, how well do you:

	Worse	About Average	Better	
a. Get along with your brothers & sisters?	☐	☐	☐	☐ I have no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Get along with your parents?	☐	☐	☐	
d. Do things by yourself?	☐	☐	☐	

VII. Performance in academic subjects. ☐ **I do not attend school because** ______________________

____

Check a box for each subject that you take	Failing	Below Average	Average	Above Average
a. English or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
Other academic subjects—for example: computer courses, foreign language, business. Do not include gym, shop, driver's ed., etc. e. ______	☐	☐	☐	☐
f. ______	☐	☐	☐	☐
g. ______	☐	☐	☐	☐

Do you have any illness, disability, or handicap? ☐ **No** ☐ **Yes—please describe:**

Please describe any concerns or problems you have about school:

Please describe any other concerns you have:

Please describe the best things about yourself:

Below is a list of items that describe kids. For each item that describes you ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of you. Circle the ***1*** if the item is ***somewhat or sometimes true*** of you. If the item is ***not true*** of you, circle the ***0***.

Please Print **0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True**

0 1 2 1. I act too young for my age

0 1 2 2. I have an allergy (describe): ______

______

______

0 1 2 3. I argue a lot

0 1 2 4. I have asthma

0 1 2 5. I act like the opposite sex

0 1 2 6. I like animals

0 1 2 7. I brag

0 1 2 8. I have trouble concentrating or paying attention

0 1 2 9. I can't get my mind off certain thoughts (describe): ______

______

______

0 1 2 10. I have trouble sitting still

0 1 2 11. I'm too dependent on adults

0 1 2 12. I feel lonely

0 1 2 13. I feel confused or in a fog

0 1 2 14. I cry a lot

0 1 2 15. I am pretty honest

0 1 2 16. I am mean to others

0 1 2 17. I daydream a lot

0 1 2 18. I deliberately try to hurt or kill myself

0 1 2 19. I try to get a lot of attention

0 1 2 20. I destroy my own things

0 1 2 21. I destroy things belonging to others

0 1 2 22. I disobey my parents

0 1 2 23. I disobey at school

0 1 2 24. I don't eat as well as I should

0 1 2 25. I don't get along with other kids

0 1 2 26. I don't feel guilty after doing something I shouldn't

0 1 2 27. I am jealous of others

0 1 2 28. I am willing to help others when they need help

0 1 2 29. I am afraid of certain animals, situations, or places, other than school (describe): ______

______

______

0 1 2 30. I am afraid of going to school

0 1 2 31. I am afraid I might think or do something bad

0 1 2 32. I feel that I have to be perfect

0 1 2 33. I feel that no one loves me

0 1 2 34. I feel that others are out to get me

0 1 2 35. I feel worthless or inferior

0 1 2 36. I accidentally get hurt a lot

0 1 2 37. I get in many fights

0 1 2 38. I get teased a lot

0 1 2 39. I hang around with kids who get in trouble

0 1 2 40. I hear sounds or voices that other people think aren't there (describe): ______

______

______

0 1 2 41. I act without stopping to think

0 1 2 42. I would rather be alone than with others

0 1 2 43. I lie or cheat

0 1 2 44. I bite my fingernails

0 1 2 45. I am nervous or tense

0 1 2 46. Parts of my body twitch or make nervous movements (describe): ______

______

______

0 1 2 47. I have nightmares

0 1 2 48. I am not liked by other kids

0 1 2 49. I can do certain things better than most kids

0 1 2 50. I am too fearful or anxious

0 1 2 51. I feel dizzy

0 1 2 52. I feel too guilty

0 1 2 53. I eat too much

0 1 2 54. I feel overtired

0 1 2 55. I am overweight

56. Physical problems ***without known medical cause:***

0 1 2 a. Aches or pains (*not stomach or headaches*)

0 1 2 b. Headaches

0 1 2 c. Nausea, feel sick

0 1 2 d. Problems with eyes (*not if corrected by glasses*) (describe): ______

______

______

0 1 2 e. Rashes or other skin problems

0 1 2 f. Stomachaches or cramps

0 1 2 g. Vomiting, throwing up

0 1 2 h. Other (describe): ______

______

______

0 1 2 57. I physically attack people

0 1 2 58. I pick my skin or other parts of my body (describe): ______

______

______

0 1 2 59. I can be pretty friendly

0 1 2 60. I like to try new things

0 1 2 61. My school work is poor

0 1 2 62. I am poorly coordinated or clumsy

0 1 2 63. I would rather be with older kids than with kids my own age

Please see other side

0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 64. I would rather be with younger kids than with kids my own age

0 1 2 65. I refuse to talk

0 1 2 66. I repeat certain acts over and over (describe): ____________

____

____

0 1 2 67. I run away from home

0 1 2 68. I scream a lot

0 1 2 69. I am secretive or keep things to myself

0 1 2 70. I see things that other people think aren't there (describe): ____________

____

____

0 1 2 71. I am self-conscious or easily embarrassed

0 1 2 72. I set fires

0 1 2 73. I can work well with my hands

0 1 2 74. I show off or clown

0 1 2 75. I am shy

0 1 2 76. I sleep less than most kids

0 1 2 77. I sleep more than most kids during day and/or night (describe): ____________

____

____

0 1 2 78. I have a good imagination

0 1 2 79. I have a speech problem (describe): ____________

____

____

____

0 1 2 80. I stand up for my rights

0 1 2 81. I steal at home

0 1 2 82. I steal from places other than home

0 1 2 83. I store up things I don't need (describe): ____________

____

____

0 1 2 84. I do things other people think are strange (describe): ____________

____

____

0 1 2 85. I have thoughts that other people would think are strange (describe): ____________

____

____

____

0 1 2 86. I am stubborn

0 1 2 87. My moods or feelings change suddenly

0 1 2 88. I enjoy being with other people

0 1 2 89. I am suspicious

0 1 2 90. I swear or use dirty language

0 1 2 91. I think about killing myself

0 1 2 92. I like to make others laugh

0 1 2 93. I talk too much

0 1 2 94. I tease others a lot

0 1 2 95. I have a hot temper

0 1 2 96. I think about sex too much

0 1 2 97. I threaten to hurt people

0 1 2 98. I like to help others

0 1 2 99. I am too concerned about being neat or clean

0 1 2 100. I have trouble sleeping (describe): ____________

____

____

0 1 2 101. I cut classes or skip school

0 1 2 102. I don't have much energy

0 1 2 103. I am unhappy, sad, or depressed

0 1 2 104. I am louder than other kids

0 1 2 105. I use alcohol or drugs for nonmedical purposes (describe): ____________

____

____

____

0 1 2 106. I try to be fair to others

0 1 2 107. I enjoy a good joke

0 1 2 108. I like to take life easy

0 1 2 109. I try to help other people when I can

0 1 2 110. I wish I were of the opposite sex

0 1 2 111. I keep from getting involved with others

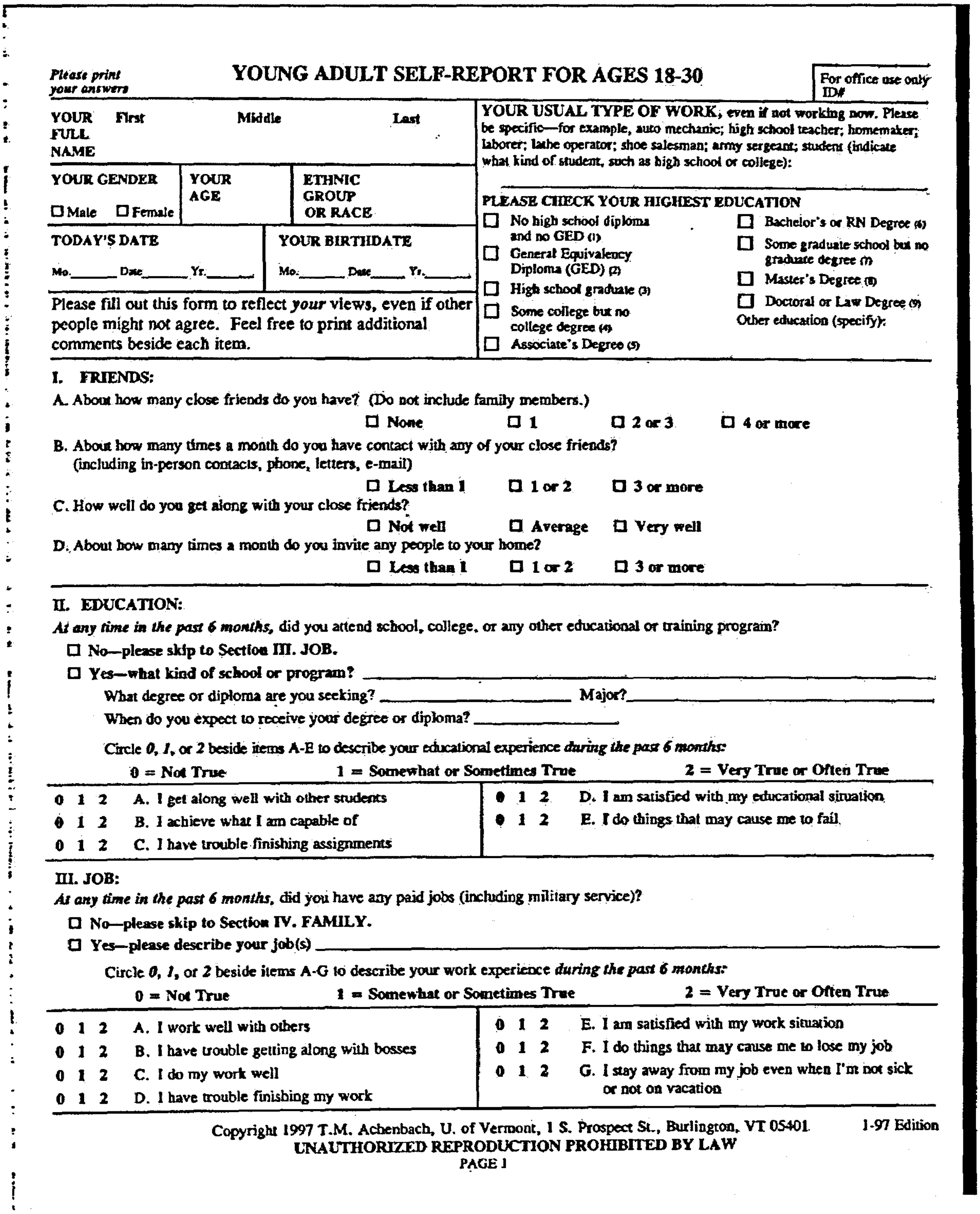
0 1 2 112. I worry a lot

Please write down anything else that describes your feelings, behavior, or interests

____

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS

Appendix 2



Please print your answers

YOUNG ADULT SELF-REPORT FOR AGES 18-30

For office use only
ID#

YOUR FULL NAME First Middle Last

YOUR GENDER ☐ Male ☐ Female

YOUR AGE

ETHNIC GROUP OR RACE

TODAY'S DATE Mo._____ Date_____ Yr._____

YOUR BIRTHDATE Mo._____ Date_____ Yr._____

Please fill out this form to reflect *your* views, even if other people might not agree. Feel free to print additional comments beside each item.

YOUR USUAL TYPE OF WORK, even if not working now. Please be specific—for example, auto mechanic; high school teacher; homemaker; laborer; lathe operator; shoe salesman; army sergeant; student (indicate what kind of student, such as high school or college):

PLEASE CHECK YOUR HIGHEST EDUCATION

- ☐ No high school diploma and no GED (1)
- ☐ General Equivalency Diploma (GED) (2)
- ☐ High school graduate (3)
- ☐ Some college but no college degree (4)
- ☐ Associate's Degree (5)
- ☐ Bachelor's or RN Degree (6)
- ☐ Some graduate school but no graduate degree (7)
- ☐ Master's Degree (8)
- ☐ Doctoral or Law Degree (9)

Other education (specify):

I. FRIENDS:

A. About how many close friends do you have? (Do not include family members.)

☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

B. About how many times a month do you have contact with any of your close friends? (including in-person contacts, phone, letters, e-mail)

☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

C. How well do you get along with your close friends?

☐ Not well ☐ Average ☐ Very well

D. About how many times a month do you invite any people to your home?

☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

II. EDUCATION:

At any time in the past 6 months, did you attend school, college, or any other educational or training program?

☐ **No—please skip to Section III. JOB.**

☐ **Yes—what kind of school or program?** __________

What degree or diploma are you seeking? __________ Major? __________

When do you expect to receive your degree or diploma? __________

Circle *0, 1*, or *2* beside items A-E to describe your educational experience *during the past 6 months:*

0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 A. I get along well with other students

0 1 2 B. I achieve what I am capable of

0 1 2 C. I have trouble finishing assignments

0 1 2 D. I am satisfied with my educational situation

0 1 2 E. I do things that may cause me to fail

III. JOB:

At any time in the past 6 months, did you have any paid jobs (including military service)?

☐ **No—please skip to Section IV. FAMILY.**

☐ **Yes—please describe your job(s)** __________

Circle *0, 1*, or *2* beside items A-G to describe your work experience *during the past 6 months:*

0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 A. I work well with others

0 1 2 B. I have trouble getting along with bosses

0 1 2 C. I do my work well

0 1 2 D. I have trouble finishing my work

0 1 2 E. I am satisfied with my work situation

0 1 2 F. I do things that may cause me to lose my job

0 1 2 G. I stay away from my job even when I'm not sick or not on vacation

PAGE 1

Please print your answers

IV. FAMILY:

Compared with others, how well do you:	Worse	Average	Better	No Contact	
A. Get along with your brothers and sisters?	☐	☐	☐	☐	☐ I have no brothers or sisters
B. Get along with your mother?	☐	☐	☐	☐	☐ Mother is deceased
C. Get along with your father?	☐	☐	☐	☐	☐ Father is deceased

V. SPOUSE OR PARTNER:

What is your current marital status?
☐ Never been married
☐ Married, living with spouse
☐ Widowed
☐ Married but separated from spouse
☐ Divorced
☐ Other—please describe: ______________

At any time in the past 6 months, did you live with your spouse or with a partner?

☐ No—please skip to Section VI.
☐ Yes—describe your living situation ______________

Circle *0, 1,* or *2* beside items A-G to describe your relationship *during the past 6 months:*

0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 A. I get along well with my spouse or partner
0 1 2 B. My spouse or partner and I have trouble sharing responsibilities
0 1 2 C. I feel satisfied with my spouse or partner
0 1 2 D. My spouse or partner and I enjoy similar activities
0 1 2 E. My spouse or partner and I *disagree* about living arrangements, such as where we live
0 1 2 F. I have trouble with my spouse's or partner's family
0 1 2 G. I like my spouse's or partner's friends

VI. Do you have any illness, disability, or handicap? ☐ No ☐ Yes—please describe:

VII. Please describe any concerns or worries you have about work, school, or other things: ☐ No concerns

VIII. Please describe the best things about yourself:

Please print your answers

IX. **Below is a list of items that describe people. For each item, please circle *0, 1,* or *2* to describe yourself *over the past 6 months.* Please answer all items as well as you can, even if some do not seem to apply to you.**

0 = Not True **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. I act too young for my age
0 1 2 2. I make good use of my opportunities
0 1 2 3. I argue a lot
0 1 2 4. I work up to my ability
0 1 2 5. I act like the opposite sex
0 1 2 6. I use drugs (other than alcohol) for nonmedical purposes (describe): ____________
0 1 2 7. I brag
0 1 2 8. I have trouble concentrating or paying attention
0 1 2 9. I can't get my mind off certain thoughts (describe): ____________
0 1 2 10. I have trouble sitting still
0 1 2 11. I am too dependent on others
0 1 2 12. I feel lonely
0 1 2 13. I feel confused or in a fog
0 1 2 14. I cry a lot
0 1 2 15. I am pretty honest
0 1 2 16. I am mean to others
0 1 2 17. I daydream a lot
0 1 2 18. I deliberately try to hurt or kill myself
0 1 2 19. I try to get a lot of attention
0 1 2 20. I destroy my things
0 1 2 21. I destroy things belonging to others
0 1 2 22. I worry about my future
0 1 2 23. I break rules at school, work, or elsewhere
0 1 2 24. I don't eat as well as I should
0 1 2 25. I don't get along with other people
0 1 2 26. I don't feel guilty after doing something I shouldn't
0 1 2 27. I am jealous of others
0 1 2 28. I get along badly with my family
0 1 2 29. I am afraid of certain animals, situations, or places (describe): ____________
0 1 2 30. My relations with the opposite sex are poor
0 1 2 31. I am afraid I might think or do something bad
0 1 2 32. I feel that I have to be perfect
0 1 2 33. I feel that no one loves me
0 1 2 34. I feel that others are out to get me
0 1 2 35. I feel worthless or inferior
0 1 2 36. I accidentally get hurt a lot
0 1 2 37. I get in many fights
0 1 2 38. I get teased a lot
0 1 2 39. I hang around with others who get in trouble
0 1 2 40. I hear sounds or voices that other people think aren't there (describe): ____________
0 1 2 41. I am impulsive or act without thinking
0 1 2 42. I would rather be alone than with others
0 1 2 43. I lie or cheat
0 1 2 44. I bite my fingernails
0 1 2 45. I am nervous or tense
0 1 2 46. Parts of my body twitch or make nervous movements (describe): ____________
0 1 2 47. I lack self-confidence
0 1 2 48. I am not liked by others
0 1 2 49. I can do certain things better than other people
0 1 2 50. I am too fearful or anxious
0 1 2 51. I feel dizzy or lightheaded
0 1 2 52. I feel too guilty
0 1 2 53. I eat too much
0 1 2 54. I feel overtired
0 1 2 55. I am overweight

56. Physical problems *without known medical cause:*

0 1 2 a. Aches or pains (*not* stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feel sick
0 1 2 d. Problems with eyes (*not* if corrected by glasses) (describe): ____________
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Heart pounding or racing
0 1 2 i. Numbness or tingling in body parts
0 1 2 j. Other (describe): ____________

0 1 2 57. I physically attack people
0 1 2 58. I pick my skin or other parts of my body (describe): ____________
0 1 2 59. I fail to finish things I should do
0 1 2 60. There is very little that I enjoy
0 1 2 61. My school work or job performance is poor
0 1 2 62. I am poorly coordinated or clumsy
0 1 2 63. I would rather be with older people than with people of my own age

Please see other side

Please print your answers

0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 64. I would rather be with younger people than with people of my own age
0 1 2 65. I refuse to talk
0 1 2 66. I repeat certain acts over and over (describe): ____________
0 1 2 67. I have trouble making or keeping friends
0 1 2 68. I scream or yell a lot
0 1 2 69. I am secretive or keep things to myself
0 1 2 70. I see things that other people think aren't there (describe): ____________
0 1 2 71. I am self-conscious or easily embarrassed
0 1 2 72. I set fires
0 1 2 73. I meet my responsibilities to my family
0 1 2 74. I show off or clown
0 1 2 75. I am shy or timid
0 1 2 76. My behavior is irresponsible
0 1 2 77. I sleep more than most other people during day and/or night (describe): ____________
0 1 2 78. I have trouble making decisions
0 1 2 79. I have a speech problem (describe): ____________
0 1 2 80. I stand up for my rights
0 1 2 81. I worry about my job or school work (describe): ____________
0 1 2 82. I steal
0 1 2 83. I store up too many things I don't need (describe): ____________
0 1 2 84. I do things other people think are strange (describe): ____________
0 1 2 85. I have thoughts that other people would think are strange (describe): ____________
0 1 2 86. I am stubborn, sullen, or irritable
0 1 2 87. My moods or feelings change suddenly
0 1 2 88. I enjoy being with other people
0 1 2 89. I am suspicious
0 1 2 90. I drink too much alcohol or get drunk
0 1 2 91. I think about killing myself
0 1 2 92. I do things that may cause me trouble with the law (describe): ____________
0 1 2 93. I talk too much
0 1 2 94. I tease others a lot
0 1 2 95. I have a hot temper
0 1 2 96. I think about sex too much
0 1 2 97. I threaten to hurt people
0 1 2 98. I like to help others
0 1 2 99. I enjoy a good joke
0 1 2 100. I have trouble sleeping (describe): ____________
0 1 2 101. I have a good imagination
0 1 2 102. I don't have much energy
0 1 2 103. I am unhappy, sad, or depressed
0 1 2 104. I am louder than others
0 1 2 105. I like to make others laugh
0 1 2 106. I try to be fair to others
0 1 2 107. I feel that I can't succeed
0 1 2 108. I like to take life easy
0 1 2 109. I like to try new things
0 1 2 110. I wish I were of the opposite sex
0 1 2 111. I keep from getting involved with others
0 1 2 112. I worry a lot
0 1 2 113. I am too concerned about how I look
0 1 2 114. I fail to pay my debts or meet other financial responsibilities
0 1 2 115. I have nightmares
0 1 2 116. I worry about my relations with the opposite sex

117. *In the past 6 months*, about how many times per day did you use tobacco (including smokeless tobacco)?
______ times per day.

118. *In the past 6 months*, on how many days were you drunk?
______ days.

119. *In the past 6 months*, on how many days did you use drugs for nonmedical purposes (including marijuana, glue, cocaine, and any other drugs)? ______ days.

X. Please write down anything else that describes your feelings, behavior, or interests:

PAGE 4 PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS

Appendix 3

Treatment adherence: an exploratory study of psychosocial wellbeing

Study Code……..

Managing Your Health

- The Adolescent Service aims to understand the difficulties some young people have with using treatment plans and the advice they are given to manage their own health, particularly young people with chronic illness.
- We believe that the best way to understand the difficulties is ask to young people themselves about their own experiences.
- The treatment advice given by doctors and other health workers may include tests, medications, appointments, follow up, physio, diet or things like not smoking or not drinking alcohol.
- Sometimes the advice or treatment may be difficult to understand, it might be that the young person does not think the advice is useful, finds treatment too hard, too painful or embarrassing, may might not understand why they are doing it or simply do not want to do it.

* * *

Please read each question and decide which answer best fits your situation and then circle the number under that answer. Some questions will ask you to write your own answers in the space provided or if you run out of room you can use the back. Thank you for taking time to do this.

1. How well do you believe you are able to manage your own health with the advice given to you by your doctors?

Please circle the number that best describes you.

Not very well at all	Sometimes well	Generally well	Nearly always manage well	Always manage well
1	2	3	4	5

2. Do you agree that the advice given to you by your doctors to manage your health actually improves your health?

Please circle the number that best describes how you feel.

Strongly disagree	Mildly Disagree	Neither disagree or agree	Mildly agree	Strongly agree
1	2	3	4	5

Please continue over the next page

Treatment adherence: an exploratory study of psychosocial wellbeing

Managing Your Health

3. Do you agree that when you don't take the advice given to you to manage your health, it will harm your health?

Please circle the number that best describes how you feel.

Strongly disagree	Mildly disagree	Neither disagree or agree	Mildly agree	Strongly agree
1	2	3	4	5

4. Do you have difficulties doing all the things asked of you to manage your health?

Please circle the number that best describes how you feel.

Always have difficulty	Sometimes have difficulty	Generally manage okay	Rarely have difficulty	Never have difficulty
1	2	3	4	5

5. If you have difficulties doing all the things asked of you to manage your health what sort of difficulties do you have?

____

____

____

____

____

____

____

Please continue over the page

6. Do you have concerns about yourself apart from the reason you are in hospital?

Yes ☐ No ☐

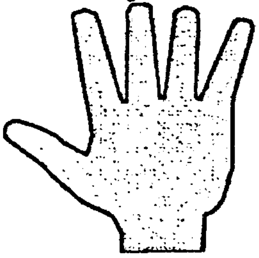
If you answered yes what concerns do you have?

7. Do you have other concerns about your life apart from the reason you are in hospital?

Yes ☐ No ☐

If you answered yes what concerns do you have?

Thank you for taking the time to fill this in.



The End