

Care Coordination for Children Transitioning from Hospital to Home:  
A Literature Review

by  
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Supervisory Committee

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**Abstract**

The changing epidemiology of child health means that an increasing number of children with chronic and complex health issues live well into adulthood, most of whom will require life-long care coordination. The needs of these children cross multiple disciplines and involve many subsystems. The current economic climate places heavy demands on health care systems to exercise cost containing measures. Services are fragmented, hospital discharges are expedited, and patients are expected to assume a greater degree of responsibility for their own care. Coordination of the care of pediatric patients is left predominantly in the hands of parents with little knowledge of health care system functioning or awareness of available resources.

In order to ensure comprehensive patient care specific to patient needs it is necessary to identify gaps in service provision and advocate for the development of programs to address the fragmentation in care. Existing models of care coordination and chronic care management have focused predominantly on the adult population. This paper will focus on meeting the needs of children with complex and chronic medical conditions by exploring the various models for care and theory underpinning nursing children and families experiencing transitions. Suggestions for application of theory in practice will be achieved through the presentation of a case example.

Transitional Care Coordination	4
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## **Table of Contents**

Supervisory Committee.....	2
Abstract.....	3
Table of Contents.....	4
Acknowledgements.....	7
Part I: Overview.....	19
Introduction and Background.....	10
Coordinating Care for Children .....	11
Problem Statement.....	12
Objectives.....	12
Practice Context .....	13
Economic Context .....	14
Health Inequities and Vulnerable Populations.....	15
Scope of this Project.....	16
Part II: Literature Review.....	18
Literature Review Search Criteria.....	19
Common Issues Associated with CHD and Chronic Illness.....	20
Nutrition .....	20
Dental care and bacterial endocarditis prevention .....	21
Other considerations .....	22

Transitional Care Coordination	5
Neurodevelopment and cognitive outcomes .....	23
Behavioral and emotional adjustment .....	25
Definitions and Conceptual Clarification.....	26
Children with special health care needs .....	26
Chronic disease .....	28
Care coordination .....	30
Case management and discharge planning .....	31
Transitional care coordination .....	32
Theoretical Approaches to Transitional Care.....	33
Family-centred care .....	34
Family systems nursing .....	35
Transition theory .....	37
Adaptation .....	40
Uncertainty and meaning .....	43
Stress and coping .....	45
Existing Models for Transitional Care and Chronic Care Coordination.....	47
The Chronic Care Model .....	47
Evidence of model benefits .....	51
The Transitional Care Model .....	54
The dimensions of the transitional care nurse role .....	55
Evidence of model benefits .....	58
Marrying the Models.....	60

Transitional Care Coordination	6
Health Literacy.....	60
Definition of health literacy .....	60
Prevalence of low health literacy .....	61
Implications of low health literacy for health and well-being .....	63
Families and literacy .....	64
Recommendations for overcoming health literacy barriers .....	65
Part III: Locating the Issue Within Advanced Practice Nursing.....	68
APN Leadership.....	69
Defining characteristics of CNS leadership .....	72
Developing the leader within .....	74
The Role of Research in CNS Practice.....	77
The APN as Transitional Care Coordinator .....	79
Part IV: Case Example.....	82
Part V: Discussion.....	88
Recommendations to Address Service Gaps.....	89
Directions for Future research.....	90
Conclusion.....	91
References.....	93
Appendix A.....	105
Appendix B.....	106

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**Part I: Overview**

## **Introduction and Background**

A congenital heart defect (CHD) refers to a condition where the heart fails to form properly in utero. Sometimes misleadingly referred to as a congenital heart disease, it is not a disease process, rather, it is an anatomical abnormality. Over 35 types of heart defect have been identified, ranging in severity from completely benign to life threatening (Smith, 2001). The incidence of CHD among Canadian children is estimated to be approximately 1 in 70 which amounts to 12 children being born with a heart defect daily (Canadian Congenital Heart Alliance, 2009). “CHD is the second most prevalent chronic illness in childhood” (Green, 2004, p.282).

Although a cause and effect has been established between certain genetic and environmental factors and CHD, “in the majority of cases the cause at this time is considered multi-factorial, with no specific identifiable trigger” (Smith, 2001, p.308). Congenital abnormalities and single gene defects that are commonly associated with CHD include Down Syndrome (Trisomy-21), Trisomy-18, Trisomy-13, Turner Syndrome, Cri du chat Syndrome, Velo-cardio-facial Syndrome / DiGeorge Syndrome / 22q11.2 microdeletion, Williams Syndrome, CHARGE Syndrome, Marfan Syndrome, and Noonan Syndrome. It is beyond the scope of this paper to provide a detailed explanation of each syndrome, yet it is important to be aware that CHD does not always occur in isolation, and the management of the care needs for this population is multidimensional.

Historically, outcomes for children born with CHD were poor, however, due to technological advancements in both diagnostics and treatment, 95% of children with CHD are expected to live well into adulthood (Canadian Congenital Heart Alliance, 2009). Between 1979 and 1997 there was a 39% decrease in mortality among children with CHD (Green, 2004, p.280).

As a result, the epidemiology of CHD has changed dramatically with an 85% increase in adults living with CHD between 1985 and 2000 (Green, 2004; Marelli, Mackie, Ionescu-Ittu, Rahme, & Pilote, 2007, p.170). By the year 2000, the number of adults and children living with CHD were almost equal (Marelli et al., 2007, p.170). Recent research indicates that the majority of adults with CHD are adolescents and young adults, therefore, the number of older adults with CHD will continue to rise as this population ages.

### **Coordinating Care for Children**

According to Betz and Redcay (2005), 90% of children diagnosed with special health care needs survive into adulthood (p.49). The needs of these children cross multiple disciplines and involve many subsystems. The American Academy of Pediatrics have designated care coordination as the service of primary importance for children with chronic health conditions (Gupta, O'Connor, & Quezada-Gomez, 2004). A study by Gupta et al. (2004) demonstrated a discrepancy between physician reports of the provision of care coordination services and actual physician activities, indicating the need for a clear definition of care coordination to contribute to consistent service provision. The authors revealed that lack of time was the most commonly reported barrier to providing care coordination services. Increasing productivity demands limits time available for non-clinical care coordination activities by primary care physicians. Although this study examines care coordination in primary care practice, the reality of the health care systems in times of budget constraints means that time for care coordination is limited across all care settings. However, the importance of incorporating care coordination as a preventative measure for maintaining optimal health and wellness, and, in turn, reducing acute care expenditures, cannot be overlooked.

**Problem Statement**

The changing epidemiology of child health means that there are more children with chronic and complex health issues in our community, most of whom will require life-long care coordination. Children requiring complex care from multiple sources will find a variety of eligibility criteria for services, a lack of communication among service providers, and a great deal of inconsistency between organizations. Coordination of care is left predominantly in the hands of parents with little knowledge of health care system functioning and little awareness of available resources. Existing models of care coordination and chronic care management have focused predominantly on the adult population. This paper will focus on meeting the needs of children with complex and chronic medical conditions by exploring the various models for care to make recommendations for bridging gaps in pediatric services.

**Objectives**

The intent of this project is to conduct a review and synthesis of the existing literature with the objective of gaining a theoretical perspective of possible approaches to providing transitional care to a pediatric acute care population. By developing a portrait of the care needs of a pediatric cardiology patient, I will demonstrate the complexity of planning involved in their care and argue the need for improved coordination between health care environments.

I will begin by describing some of the common issues associated with CHD in order to provide context to the complexity of care involved with chronic conditions such as this. I will then define the multiple and overlapping terms used in the literature to describe related services and propose a single overarching term of Transitional Care Coordination. I will discuss nursing theories that should be considered when planning transitional care coordination for children. I

intend to review the theory that underpins transitions in childhood and adolescence, particularly as it relates to illness transitions. In addition, I will explore elements of the various models of chronic care management and transitional care that would apply to the care of this specific population of patients.

In order to situate the issue within nursing, I will argue the need for advanced practice nursing leadership in enacting this type of clinical practice redesign or program development. In addition, health literacy will be discussed as it relates to knowledge transfer between nurses, patients and families. Recommendations for the application of theory in practice in the context of transitional care will be made through a case example.

### **Practice Context**

In my practice as an acute-care bedside nurse I work predominantly with pediatric cardiac patients. At BC Children's Hospital over "140 open-heart surgeries are performed every year, and more than 60 percent of those are performed on patients younger than one year old" (BC Children's Hospital [BCCH], 2010). In-patient services include a 22-bed ICU, a 48-bed special care nursery, and a 28-bed in-patient unit. In addition, there is a multidisciplinary out-patient clinic which receives in excess of 7,000 patient visits per year (BCCH, 2010).

The patient demographics include children from newborn through adolescent, of every race and ethnicity, and across all levels of socioeconomic status. From my observations it appears the younger patients, who are predominantly infants, are typically newly diagnosed and in hospital for a primary surgical repair (open heart or catheterization), staged procedures, catheter ablation of accessory electrical pathways or palliative repair. Some patients in this age group are admitted after their repair with respiratory infection, bacterial endocarditis, wound

infection, or feeding intolerance. The adolescents I have worked with generally present for pacemaker insertion, surgical revision, sudden cardiac arrest, supraventricular tachycardia, or dysrhythmias secondary to electrolyte imbalance resulting from severe anorexia or drug overdose.

Often times this population of patients requires parents to rapidly learn to provide medical care in the home following their hospital stay, sometimes for life. Some patients require enteric feedings daily, others require medication administration, and some have complex medical needs that have the potential to dominate, and conflict with, the life of the family. As a result, parents may face the burden of becoming literate in medical terminology, navigating the health care system, or balancing hospital stays with work and other family commitments.

### **Economic Context**

The current economic climate places heavy demands on health care systems to exercise cost containing measures. Services are fragmented, hospital discharges are expedited, and patients are expected to assume a greater degree of responsibility for their own care. Higher patient acuity and an increased nursing scope of practice has resulted in heavier workloads for front-line hospital-based nursing staff. Consequently, time for patient contact is reduced, nursing care is standardized and task-oriented, and opportunities to engage in dialogue focusing on the subjective experience of the patient are minimal. Aranda and Jones (2007) described this phenomenon as “distal nursing” whereby the notion of holistic practice is merely rhetorical and is incongruent with current system functioning (p.5). The authors advocate for a reassessment of nursing's mandate, to meet patients and families identified needs, while providing a realistic portrait of service provision. In order to ensure comprehensive patient care specific to patient

needs it is necessary to identify gaps in service provision and advocate for the development of programs to address the fragmentation in care.

### **Health Inequities and Vulnerable Populations**

The strain on the U.S. economy sparked by the 2008 banking crisis impacted many Canadian families who were affected by job losses, real estate depreciation, or the uncertainty of a volatile economic future. Income inequalities have been shown to be linked to health disparities, with lower income generators experiencing poorer health outcomes secondary to increased environmental and emotional stressors and an increase in engagement in damaging health behaviors (Frohlich, Ross, & Richmond, 2005). A literature review conducted by Green (2004) demonstrated that children with CHD at greatest risk of negative behavioral or psychiatric outcomes come from families with a large number of siblings, a lower socioeconomic status (SES), or lower parental education (p.281). However, these findings are not necessarily specific to families of children with CHD.

It is not uncommon to have CHD patients who present in drug withdrawal in the immediate post-natal period as a result of maternal street drug use. The outcomes for these patients are often further complicated by Ministry of Children and Family involvement and unstable parental relationships. Occasionally there are parents who are not involved with the child, as the infant is placed in protective custody immediately following their birth. These children do not get the benefit of attachment, touch, or love from their parents, and spend much of their time alone in a room while their nurse is otherwise occupied. They are eventually discharged into foster care and sent home with a stranger.

Vrijheid et al. (2000) examined the correlation between SES and congenital anomalies.

The authors found an increased prevalence of congenital abnormalities, including heart defects, with lower SES. Greater deprivation was associated with a higher prevalence of defects.

Vrijheid et al. (2000) suggested that the correlation may be attributed to environmental or occupational factors including nutritional status, lifestyle, pre-natal care, and maternal age.

BC Children's hospital serves the entire province and, as such, provides care to a large aboriginal population of patients. There have been marked disparities described between aboriginal and non-aboriginal people of Canada. This population is disproportionately affected by chronic illness, infectious disease, and suicide (Frolich et al., 2006). An awareness of the issues these populations face, including poverty, unemployment, housing, and sexual or physical abuse, is essential in ensuring care that addresses additional support and educational needs.

### **Scope of this Project**

The pediatric cardiology population often has complex needs, however, they tend not to be perceived as high priority as children with physical limitations such as cerebral palsy or those that require mechanical ventilation in the home. Programs such as the Nursing Support Services and the At Home Program provide benefits for children with physical disabilities and home administered mechanical ventilation but seldom do cardiology patients qualify for benefits like home nursing care or respite hours, leaving them with no managed community nursing care. Although this paper will use the pediatric cardiology population as an example of the complexity of care required, the need for transitional care coordination with a focus on chronic care management exists throughout all acute care areas of the hospital. The recommendations resulting from this project are highly applicable and may be applied to any pediatric patient that has complex or chronic medical conditions. Clinical practice redesign aims to create sustainable

improvement in the practice setting based on identified need for change. It encompasses a set of tools and methodologies for performance and quality improvement and can be directed at improving access to care, improving efficiency of care, improving communication, or decreasing cost of care (Health Quality Council, n.d.). It is patient-centred and the ultimate goal is to improve patient outcomes. Clinical Practice Redesign is a process that is best initiated on a small scale and through a series of tests, measures, redesigns and retests, the scope of the program can be increased. Although a practice redesign such as the one recommended in this paper may start with a single patient population, the overarching goal should be to implement the program throughout the organization.

**Part II: Literature Review**

**Literature Review Search Criteria**

The University of Victoria Library electronic search engine was used to perform a computerized search of CINAHL plus with EBESCO, Ovid Medline, and PubMed. The advanced search feature was utilized to limit literature to English language, peer reviewed articles, with a publication date range from January 1990 to January 2011. The rationale for dating back to 1990 is that many of the nursing models and theories about transitions were conceived in that decade. Search terms were applied both individually, and in various boolean combinations and included: transitional care, transitional care model, transition theory, care coordination, discharge, discharge planning, case management, chronic care coordination, hospital to home, pediatrics, children, medically complex, parental needs, uncertainty, adaptation, stress, coping, family systems nursing, and health literacy. In addition, Up to Date was consulted for current recommendations on hospital discharge planning. A Google Scholar search using the aforementioned key words was performed to locate any articles not available through the University Library. Literature was selected from peer reviewed articles in the fields of nursing, medicine, and sociology. Abstracts were reviewed and any articles related to transition between pediatric and adult care were excluded. A review of the reference lists in articles applicable to the subject of this paper directed the search for additional individual articles of interest. The search for literature on a given topic ceased when saturation was achieved and no new relevant articles were found.

**Common Issues Associated with CHD and Chronic Illness**

There are varying degrees of severity associated with CHD and the amount of care required for these children is highly individual. It is important that any nurse have an in-depth understanding of the common issues facing the population they serve in order to deliver anticipatory care and tailor education and support for caregivers. The following discussion will highlight some of these issues, in order to provide context for the case example provided in a later chapter.

**Nutrition.** Feeding difficulties and growth suppression are common among the CHD population (Smith, 2001; St. Pierre et al., 2009). “Long term malnutrition is associated with deficits in cognition and motor skills” and directly impacts surgical outcomes, hospital length of stay and patient morbidity (St. Pierre et al., 2009, p.2). Surgical intervention at an earlier age is associated with favorable outcomes for growth recovery (Smith, 2001).

The causes of feeding difficulties include vocal cord injury, prolonged intubation, and poor oral coordination (Smith, 2001; St. Pierre et al., 2009). Growth suppression is multifactorial and causative factors can include increased metabolic demands, decreased caloric intake, or malabsorption due to decreased intestinal perfusion (Smith, 2001). Coexisting congenital abnormalities such as palate malformations and tracheal fistulas, neurological deficits resulting from anoxic brain injury, and chromosomal syndromes are further contributing factors (St. Pierre et al., 2009). Infants who are tube fed from birth need extra support in the post-operative period to develop suck-swallow coordination. Gastro-esophageal reflux (GER) is common in this population, particularly in those with long term nasogastric tubes, which further complicates feeding as it becomes a source of discomfort for the patient and frequently results in

regurgitation or vomiting.

Some patients may require long term tube feeding in order to increase caloric intake while decreasing metabolic demands. Tube feeding has associated risks including aspiration, over or under feeding, GER, and infection due to contamination (Smith, 2001). In addition, parents are required to medically manage their child's feeds which may prove disruptive to the family's schedule and social life. Responding to tube-related emergencies is a commonly expressed fear among this patient population.

Parental factors can influence the success or failure of feeding attempts. In a study by Kolburn Svavarsdottir & McCubbin (1996) “infants with CHD presented indistinct cues and were significantly less responsive to their caregivers during feeding than were healthy infants” (p.208). In addition, the authors reported that parents rated infant feeding as the most time-consuming task in providing care to their child. These findings suggest an adverse effect on parent-child attachment if feedings are associated with a sense of stress and frustration for both parties, with a heavy burden of care experienced by parents.

Health care providers need to monitor weight gain using growth charts because even though a child's weight can appear to be increasing steadily, they may not be gaining at the rate expected for their age and may decrease trajectory of the growth curve. Parents can be furnished with a scale to weigh infants at home and can communicate results with their provider for tracking.

**Dental care and bacterial endocarditis prevention.** Children with CHD commonly experience enamel hypoplasia which restricts proper development of tooth enamel, causing the teeth to be more prone to dental decay (Cender, Spencer, Becker, Johnson, & Sweett, n.d.). In

addition, medications in liquid form often contain sugar to make them more palatable which can contribute to cavity formation. Education surrounding dental hygiene is paramount in the CHD population because bacteria from the oral cavity can enter the bloodstream. Certain types of CHD cause turbulent blood flow in the heart and sutures or non-biological materials that have been placed in the heart, such as a patch to close a ventricular septal defect, create a rough surface, in comparison to the smooth muscle of the heart tissue. This creates a predisposition for deposition of platelets and fibrin on the surface of the endothelium and can result in the formation of a non-bacterial thrombotic endocarditis. Bacteria in the blood stream can adhere to and proliferate within these vegetations, creating a local infection, bacterial endocarditis, that can be life threatening (Wilson et al., 2007). A blood clot can cover this area of infection and present a risk for embolism resulting in stroke or infarction. There are many ways bacteria can enter the blood stream, but proper oral hygiene, and prophylactic antibiotic treatment prior to any oral surgery which may cause bleeding, are preventative measures that the patients and families can easily incorporate into their daily routine to reduce the risk of contracting bacterial endocarditis. The nurse can educate patients and families about bacterial endocarditis but it is up to the family to inform their dentist of their medical condition.

**Other considerations.** Most children with repaired CHDs will be able to participate in physical activity with minimal limitations. Among children and adolescents that experience decreased exercise tolerance, there is a risk for stigmatization or a feeling of being different from peers. A lack of understanding contributes to the false perception that the child might arrest if they engage in strenuous physical activity. In addition, scars can impact the adolescent who has body image issues to begin with (McMurray et al., 2001). Adolescent patients need to be taught

how to educate their peers to foster a culture of approachability and understanding.

Accommodations may need to be made in schools and educators should be informed about the condition and emergency management for their affected students.

Medication administration and adherence to a medication regime is a reality of the vast majority of CHD patients. Parents may also need to be educated on wound care for their child in the immediate post-operative period. Keeping an incision clean and dry on an infant can pose special challenges. In addition, certain patients, such as those who are dependent on a Blalock-Taussig shunt to provide adequate blood flow to the pulmonary circulation, may need intermittent home oxygen saturation monitoring. Parents are sent home with a oxygen saturation monitor and instructed to monitor their child's saturations at specific times, such as during and after a feed, or when there are signs and symptoms of respiratory distress or colour change. Some patients may have recurrent cardiac arrhythmias which require monitoring and home management in the event of an occurrence. In rare cases, families may be required to use a cardiac monitor in the home. All families should consider CPR training for family members and caregivers, particularly for patients with a history of cardiac arrest.

Clearly, parents are expected to assimilate a great deal of medical knowledge and perform monitoring and procedural tasks that are typically provided by medical professionals. Some parents struggle more than others to grasp the dexterity and information required to provide safe and competent care for their children's medical requirements. When teaching families, the nurse must constantly assess for understanding and knowledge gaps and revise the educational plan to suit individual needs.

**Neurodevelopment and cognitive outcomes.** Neurodevelopmental abnormalities among

children with CHD can result from microcephaly, malnutrition, hypoxemia, infarctation secondary to cardiopulmonary bypass and deep hypothermic cardiopulmonary arrest, intraventricular hemorrhage, genetic abnormalities, or inadequate fetal development (Green, 2004; Limperopolous et al., 2001; Pye & Green, 2003). Length of hospital stay and time spent in ICU are associated with poor neurodevelopmental outcomes (Pye & Green, 2003). Neurologic deficits have been shown to affect 41% of children with CHD repairs, between ages 18 and 24 months, with 23% demonstrating global developmental delay (Pye & Green, 2003, p.154). Wray and Sensky (1999) determined that in children with CHD under the age of 3.5 years old, intellectual impairment was evident prior to surgery and continued into the post-surgical period only in those children with cyanotic heart defects. This finding suggests that chronic hypoxemia contributes to intellectual impairment, although it is possible that the lethargy and increased metabolic requirements of children with cyanotic lesions influence their ability to perform well on intellectual examinations. According to Smith (2001) “very few children are severely delayed” but many have problems with attention, speech, language and motor function (p.310). A developmental assessment should be done for each patient at regular intervals to assess for deficits and provide support and resources for early intervention.

Special developmental considerations to be raised with families include delayed milestones such as sitting, crawling, or walking resulting from the child lacking the energy for activity prior to surgical repair. The nurse must ensure the patient is seen for physical therapy, the parent is taught how to promote development, and the patient is followed by the Infant Development Program. There has been increasing interest in studying the long term effects on behavior and development in CHD patients. Improvements in technology and surgical

interventions will likely have a positive impact on patient outcomes.

**Behavioral and emotional adjustment.** Over-protectiveness or fear of upsetting the child may cause a parent to avoid discipline, influencing behavioral problems independent of neurodevelopmental factors in this population. For many children with CHD the long term outcomes for lifestyle and behavioral adjustments are not significantly different from their healthy peers (Casey, Skyes, Craig, Power, & Mulholland, 1995). Parents modify their expectations and care from that which they anticipated providing a healthy child (Pinelli, 1981). Carey, Nicholson, and Fox (2002) found that for parents of infants and young children with CHD, child-rearing practices were very similar to those of parents of healthy children. One difference was that mothers of children with CHD reported having lower expectations of their children, however, these expectations were within developmental norms.

Carey et al., (2002) found that stress levels did not differ between parents of children with CHD and parents of healthy children. In fact, parents of healthy children reported finding parenting to be more challenging than expected. These findings could be attributed to parents of children with CHD adapting to the care-giving role and the degree of stress experienced being relative to the norms expected for both the individual parent groups. Consistent with other findings, there were no differences noted in behavioral outcomes for children in either group.

The common issues discussed in this paper provide an overview of care needs for the CHD population. Many of these same issues are experienced by other patient populations and other diagnostic categories may be associated with unique issues. In developing any new program, it is necessary to review the existing literature to develop a portrait of the care needs for that population.

### **Definitions and Conceptual Clarification**

There have been various terms used to describe children with special health care needs, chronic illness, and care coordination services. A lack of any consistent definition makes it difficult to compare research on outcomes for services designed to meet the needs of certain patient populations. In proposing program development, it is essential to start with defining terms and clarifying concepts related to the services that will be provided. This allows for a clear understanding of the population those services are designed for and the specific functions of the program.

**Children with special health care needs.** McPherson et al. (1998) emphasized the need to clearly define a population for which services are being developed. As such, the authors were a part of a working group under the United States Federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs whose aim was to address the development of a new definition for children with special health care needs. The resulting definition is as follows:

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (p.138).

According to the authors, risks for physical, developmental, behavioral, and emotional conditions can be biological or environmental. Biological risk factors include “very low birth weight, the presence of certain metabolic deficiencies, and the existence of some chromosomal abnormalities” (McPherson et al., 1998, p.138). Environmental risk factors include economic

and social risk factors such as “extreme poverty, absence of social support, and child abuse or neglect” (McPherson et al., 1998, p.138). In addition, risk factors in the physical environment such as pollution or second-hand smoke can contribute to, or worsen, certain chronic conditions. A further description of health and related services is provided by McPherson et al. (1998). The authors state that in order to maintain health functioning of children, those with special needs may require specialist nursing or physician services, occupational, physical, or speech therapy, home nursing, family support services, medical equipment and supplies, educational services, transportation, or social services (McPherson et al., 1998, p.139). However, the authors caution that not every child will need the full scope of services available, therefore, it should not be assumed that expanding the scope to include more children in a definition of those with special needs will be more costly to the health care system. On the contrary, the authors believe that a preventative health care approach can decrease overall health care expenditures (McPherson et al., 1998).

This definition has been accepted and used by the Academy of Pediatrics and multiple advocacy groups, however, Wise, Huffman, and Brat (2007) caution that this definition represents a highly heterogeneous group of children and blurs the distinction between children with special needs and disabled children. Certainly, many children with a CHD would qualify as having special health care needs, according to the CSHCN definition.

An equally heterogeneous definition of children and youth with special needs is provided by the Canadian Council on Social Development (CCSD, 2001). They described this population as consisting of “children/youth with physical disabilities; children/youth with chronic physical health problems; children/youth with emotional health problems; children/youth with

developmental disabilities; and children/youth with learning disabilities” (CCSD, 2001, p.8).

The National Longitudinal Survey of Children and Youth (NLSCY) included diagnoses such as “allergies, asthma, bronchitis, a heart condition, epilepsy, cerebral palsy, kidney disease, mental handicap, learning disability, emotional problem, some other condition, or an activity limitation” as qualifiers for children with a chronic condition (CCSD, 2001).

Definitions this broad may not be effective for defining children who are eligible for certain programs for which funding is limited. In this case, an organization may wish to capture a specific subgroup of children when defining the population their services are designed to assist. In addition, assessment tools for care needs and health risks may assist the care provider in categorizing patients according to extent of care coordination needed to manage their chronic condition and provide the basis for referral to a care coordination program.

**Chronic disease.** Although statistics abound to depict the prevalence, incidence and severity of chronic illness among the adult population, data on children are difficult to locate, which may be in part due to a lack of a universal definition describing this population. For example, in the United States, 30% of children report having a chronic health condition, however, included in this figure are chronic conditions such as obesity and attention deficit/hyperactivity disorder which do not require the same degree of management and care coordination as a condition such as cerebral palsy or cystic fibrosis (Wise et al., 2007, p.5).

The World Health Organization (WHO, 2011) describes chronic disease as “of long duration and generally slow progression.” The WHO (2011) claims that chronic diseases represent 60% of deaths worldwide and are the leading cause of mortality and chronic health conditions (para. 1). According to Statistics Canada (2003)

A disability due to one or more chronic health conditions affects about 118,000 children aged 0 to 14, representing 65% of children with disabilities (2.1% of all children). Half of children aged 0 to 14 with this type of disability are limited by a single chronic health condition, nearly 30% by two such conditions, and more than 20% by three or more (para. 3).

Mirolla (2004) reported that seven categories of chronic conditions (cardiovascular disease, cancer, COPD, disorders of the endocrine, musculoskeletal, and nervous system, and mental illness) account for \$24 billion in annual Canadian health care expenditures, or 42% of all health care spending for all age groups (p.4). A seldom considered economic impact relates to work hours lost due to sickness or disability and premature death. Mirolla (2004) estimates these losses to amount to a staggering \$54.4 billion a year. In comparison, Anderson and Knickman (2001) reported that in 2000 chronic conditions accounted for 75% of health care spending in the United States for all age groups. The amount is projected to increase to 80% by the year 2020 (Anderson & Knickman, 2001, p.147).

Adults with chronic illness report receiving contradictory information and different diagnoses for the same illness from varying care providers; parents of children with chronic illness may face the same frustrations (Anderson & Knickman, 2001, p.147). More research is needed to analyze the prevalence of specific chronic illnesses among children and the associated costs to the health care system. Chronic care management has the potential to decrease the costs associated with hospital admissions and physician fees. More attention is needed to explore how services can be designed to meet the needs of this population more efficiently and cost effectively.

**Care coordination.** According to Wise et al. (2007) the lack of a universal definition for care coordination may be due to differences in the way care coordination is enacted among various patient populations. The authors cite the AAP definition that “care coordination occurs when a specified care plan is implemented by a variety of service providers and programs in an organized fashion” (Wise et al., 2007, p.8). The goals of care under this definition include improving access to integrated services, avoiding duplication in services, decreasing costs and improving individual outcomes (Wise et al., 2007). However, Wise et al. (2007) argue that this definition was developed on the basis of two empirical studies, one which is dated, the other has a relatively small sample size.

In a review of the literature, Wise et al. (2007) discovered that most definitions for care coordination developed subsequent to the AAP definition relate to the medical home concept of care provision. The medical home concept is based on preventative care principles and maintains patients records in a central database. The medical home aims to create ease of access, continuity of care, facilitation with referrals to consultants, and interaction with schools and community resources (Wise, et al., 2007). The authors report that in 2002 the AAP supported the medical home model as a means of care coordination, however, the framework was not directed solely at children with special health care needs (CSHCN). This was rectified in 2005 by an AAP statement directed specifically at care for CSHCN which expanded the original definition to include that care coordination “involves needs identification, assessment, prioritizing and monitoring” (Wise et al., 2007, p.11). This definition rightly places priority on children who are identified as having the greatest need for monitoring and care management.

The medical home model is a primary care, physician-led service which would be useful

for managing patient's needs once they have returned to the community after initial hospitalization for their condition for continued monitoring and care management. However, it does not address the need for coordinating care of patients while in the hospital, regardless of length of stay, and in the immediate post-hospitalization period as they transition home with all the changes that accompany their new diagnosis. Care-coordination and self-management education needs to start while patients are still in hospital to ensure seamless transitions. Furthermore, nurses are well suited to enact this role of transition care coordinator, as I will argue in a later section of this paper.

**Case management and discharge planning.** A variety of terms are used in the literature to describe the programs and services that involve case management activities. In addition, case management is enacted differently among various disciplines. Case management may be known by other terms such as care coordination, continuity coordination, or service integration (Lyon, 1993). The National Case Management Network of Canada (2011) defines case management as

A collaborative client-driven process for the provision of quality health care and support services through the effective and efficient use of resources. Case Managers support the clients' achievement of safe, realistic and reasonable goals within a complex health care, social, and fiscal environment (para. 1).

The American Nurses Association defined case management as “a dynamic and systematic collaborative approach to providing and coordinating health care services to a defined population” (Hamric, Spross, & Hanson, 2004, p.621). The aim is to provide continuity in facilitating discharge within an appropriate time-frame, decrease fragmentation in care and duplication in services, and contain costs, while meeting individual health needs and improving

patient outcomes (Hamric et al., 2004; Lyon, 1993). These definitions are very broad and have strikingly similar features to the AAP goals of care coordination. According to Lyon (1993), it would be unrealistic for primary care nurses to take on the added responsibility of case management for their patients. The depth and breadth of case management requires staff that can assess, plan and implement a wide range of services and have a current working knowledge of the resources and services available in the community in order to reduce duplication of services.

Alper, O'Malley, and Greenwald (2010) defined discharge planning as the “development of an individualized discharge plan for the patient prior to leaving the hospital, to ensure that patients are discharged at an appropriate time and with provision of adequate post-discharge services” (p.3). Interestingly, the authors describe discharge planning as enacted by a case manager. Alper et al. (2010) believed discharge planning should be initiated for any patients requiring services in the home or transfer to another care facility. According to the authors, discharge planning activities include medication reconciliation, creation of a discharge summary to ensure communication with aftercare providers, and a review of patient instructions including provision of materials to reinforce teaching (Alper et al., 2010). However, in my experience working in a centralized referral center in British Columbia, Canada, these activities have been performed by physicians and those with the title “discharge planner” typically involve themselves in assessing the patients' need for medical equipment and supplies once home, ensuring staff nurses have provided all the necessary education for caregivers to manage the patients condition, coordinating community health services, and facilitating communication between interdisciplinary team members.

Holland and Harris (2007) reviewed the literature in order to compare the concepts

underlying the various definitions used to describe discharge planning activities. The authors created a conceptual model which depicts coordination of care as management of services among different providers according to an individualized care plan. According to the authors, coordination of care is an element of both discharge planning and transitional care. They further delineate discharge planning as the process bounded by the time period between hospital admission and discharge. Transitional care, on the other hand, incorporates elements of discharge planning but spans both the pre-hospital discharge period to care in the post-hospital setting.

**Transitional care coordination.** For the purpose of this paper, consistent with the definition of Brooten et al. (2002), the concept of transitional care coordination (TCC) will encompass hospital-based assessment, consultation, complex discharge coordination, interdisciplinary liaison, home visits following discharge, and telephone follow-up for children with complex and chronic medical needs. TCC is considered, in this sense, a form of case management and encompasses care coordination, chronic care management, discharge planning, and transitional care.

### **Theoretical Approaches to Transitional Care**

An ideal theory “brings the knowing and doing of the nurse together” (Alligood & Tomey, 2006, p.57). “Theory often brings together research findings in a way that helps practice be more purposeful, systematic, and comprehensive” (Hamric, Spross, & Hanson, 2009, p.141). Theory assists us in our ability to explain and anticipate phenomenon when performing assessments and it informs our interventions. Theory can help us identify barrier and facilitators to a given situation and assists in tailoring an approach to care with these in mind.

Several existing nursing theories can inform practice related to transitional care. Family-centred care is central to pediatric nursing practice and family systems nursing can provide a framework for assessment and intervention to guide nursing action. Both family systems nursing and transition theory are rooted in systems theory. Transition theory helps us understand the multi-dimensional and overlapping factors that influence successful transition. Awareness of the processes of adaptation and stress and coping, and the influence of uncertainty and meaning, can allow the nurse to draw upon family strengths and steer clear of barriers that may derail successful transition. Therefore, knowledge in multiple nursing theories allows a nurse to tailor individual care through theory integration specific to the patient and context.

**Family-centred care.** Pediatric nursing is synonymous with family nursing because a pediatric nurse rarely cares for a patient in isolation of their family context. Allen (1981) declared that “health is a phenomenon of a family or a group, not of an individual” (p.5). Working with a family through the acute illness to chronic wellness transition involves a shift in perspectives over the course of the illness trajectory. In the hospital, the immediate urgency to provide treatment and obtain optimal patient outcomes necessitates a conceptualization of the family as *context*. This is the prevailing perspective in a family-centred care model where the focus on family is secondary to the focus on the *individual client* (Friedman, Bowden, & Jones, 2003). The context, and the medical situation, will dictate the level of family interaction most appropriate. In a critical situation, the medical team may take over care and treatment while the family watches from the sidelines. However, as acuity decreases, the family becomes increasingly involved in the planning and provision of direct care.

Parents may overlook their own needs and risk caregiver burnout, particularly in the first

year from diagnosis when lifestyle and role adjustments are most prominent. During this period mothers have been found to be at increased risk of developing clinical depression (Narramore, 2008). Some parents fail to recognize the need for help or believe that asking for help means they have failed as a caregiver (Narramore, 2008). Interestingly, the severity of the CHD, and the complexity of the surgery and hospital stay required, does not directly translate into the level of psychological stress experienced by parents, perhaps because “for parents, there is no such thing as 'minor' surgery where *their* child is concerned” (Darbyshire, 2003, p.295). However, there is a correlation between severity of disability in a child with parental depression scores (Narramore, 2008, p.104). Therefore, the nurse must be cognizant of the potential for caregiver burden and provide care and support to the child's caregiver.

**Family systems nursing.** As the focus of nursing care progresses from assisting the patient and family through hospitalization and discharge to providing care in the home or on an outpatient basis, the emphasis must shift to a focus on the *family as client* (Friedman et al., 2003). From this lens, the family is considered a system in constant interaction with each other and their environment. Working with families to facilitate their adaptation to living with chronic illness is best achieved with a theoretical approach to practice. Family systems nursing (FSN) provides an appropriate theoretical basis for this type of nursing work.

Wright and Leahey (1990) were among the first theorists to apply the logic of systems theory to nursing care of families. From this perspective, clients are viewed as a member of a system of interrelated beings where the presence of illness or health issues impacts the family as a whole. The focus is on the interrelationship between members that make up the system and the interaction within and between systems. The health care system, including nurses, are another

interacting system, the proximity of which depends on the context of the situation. In other words, the extent to which the family allows a nurse to enter the family's internal boundaries depends on the immediate needs of the family. Often there is a specific problem that brings the nurse into the relationship. The nurse is not required to solve the problem, rather, the purpose is to help the family recognize adaptive or maladaptive functioning, highlight strengths and capacities, and facilitate the achievement of goals developed in collaboration with the family. This requires a shift from a deficit perspective where families are incapable of coping or achieving health related goals without the assistance of a health professional to a strengths-based approach where the focus is on using the family's capacities and resources to achieve their goals (Feeley & Gottlieb, 2000). Interventions do not have pre-defined outcomes “it is the psycho-biological-spiritual structure of the client/family that determines both the fit of the intervention for the family and, when there is a fit, the family's response (Robinson & Wright, 1995, p.329). Bell (1996) considers this level of theory application to be representative of advanced practice nursing in that it requires “the ability to deal with multiple systems simultaneously” (p.245).

The Calgary Family Assessment Model (CFAM) and the Calgary Family Intervention Model (CFIM) are frameworks developed to guide practice based in FSN (Robinson & Wright, 1995; Wright & Leahey, 2005). Assessments guided by CFAM use tools and circular questioning to elicit information from families. CFIM suggests interventions the nurse can utilize to “influence change in the cognitive, affective, and/or behavioral domains of family functioning” (Robinson & Wright, 1995, p.331).

The scope of FSN is extensive enough to be inclusive of all concepts within Fawcett's nursing metaparadigm of person, environment, health and nursing (Kim, 1989; Kozier, 2000).

However, given the degree of interrelationship between the nurse and the family inherent in a FSN approach, the metaparadigm topology developed by Kim (1989) is a more appropriate tool for analysis. Kim's (1989) metaparadigm contains four domains: client, client-nurse, practice and environment. Family systems theory resides within and across these domains to varying degrees. The holistic perspective of humans fit both within the client domain, as well between the client and environment domains, in that humans are considered in the context of their environment, and are believed to engage in a constant dynamic interaction with both internal and external environments. In addition, the client is the family and the family is a system, therefore the concept of systems, and the study of relational dynamics, structure and function within systems, resides in the client domain. The relationship and resulting communications that occur between the nurse and family as a result of collaborative nursing practice reside within the client (family)-nurse domain which intersects with the practice domain. Systems theory is not unique to the discipline of nursing, however, family systems nursing is unique to nursing practice.

**Transition theory.** Kralik, Visentin and van Loon (2006) conducted a comprehensive literature review to determine how the term transition is used in health care. The authors concluded that a transition is the response to change and involves adaptation to a new situation over time. In other words, transition is more complex than change alone, it is the process of incorporating change into life (Kralik et al., 2006). Chick and Meleis (1986) defined transition as “passage from one life phase, condition, or status to another...transition refers to both the process and the outcome of complex person-environment interactions” (p.239-240). Transitions involve changes in roles, identity, relationships and behaviour (Schumacher & Meleis, 1994, p.121). Transitions generally possess an “entry, passage, and exit” (Chick & Meleis, 1986).

However, it is impossible to place fixed boundaries on a transition period by attempting to define a beginning and end-point as the process is dynamic and the experience differs for each individual or family, in part due to the multiple internal and external factors that affect transitions. In addition, boundaries flex and recede and phases can overlap. Interspersed throughout each transition are various critical events that can disrupt flow and heighten vulnerability. Transitions are dynamic and cyclical and can be recurring (Kralik et al., 2006).

Transitions can be categorized across different events: health-illness, developmental or life cycle, and situational (Chick & Meleis, 1986; Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Schumacher & Meleis, 1994). Transition processes are complex and may occur simultaneously or sequentially. In addition, the context in which a transition takes place influences the impact, which contributes to the lack of uniformity in how transitions are experienced. Examples of developmental and lifespan transitions that a pediatric nurse might encounter include becoming a parent, adolescence, and death (Meleis et al., 2000). Situational transitions that might be experienced by pediatric patients and their families could include transitions in educational roles, changes in professional roles such as taking maternity leave or having to alter employment to accommodate care-giving, changes in environment such as moving to a new home, role changes such as becoming a family care-giver, and immigration (Schumacher & Meleis, 1994). Nurses most often are connected with patients through health/illness transitions such as a new diagnosis, surgery, rehabilitation, recovery, transition among levels of health care system, and transition between the hospital and the home environment (Meleis et al., 2000).

Pediatric nurses will often encounter patients experiencing multiple transitions. Some of

these may be positive transitions, but superimposed upon them is a negative transition which can cause added stress on the positive transition. At times, one transition may derail another. For example, a family may decide to move to a larger home to accommodate a new baby in the family, but upon diagnosis of an illness, the move may no longer be possible because of the cost associated with prolonged hospital stays, loss of employment, and medical treatment. With children, illness can delay development, another example of the interaction of transitions.

Both the parents and the child are experiencing transitions, some are similar, and others differ between the two. For example, parents of a newborn diagnosed with an illness are experiencing the transition to parenthood along with the transition to care-giving within the illness transition. The child is experiencing developmental transitions of infancy, including beginning to form attachment to parents, along with the illness transition.

Chick and Meleis (1986) proposed that transitions are a central concept in nursing and the antecedent events of developmental, situational, or health/illness transitions are mediated by the individual, environment, and nursing therapeutics. The outcomes of successful transition facilitation are restoration, maintenance, protection, and promotion of health (p.244).

A framework for assessment is needed to understand the individual transition experience. Schumacher and Meleis (1994), in their model on transitions, identified personal and environmental factors that can affect the transition process which include “meanings, expectations, level of knowledge and skill, the environment, level of planning, and emotional and physical well-being” (Schumacher & Meleis, 1994, p.121). Meaning relates to how an individual perceives the transition. The importance of considering meaning is in viewing the transition from the subjective perspective of the individual affected by it. Meaning is impacted

by a person's expectations. Uncertainty stems from not knowing what to expect as well as from a lack of general knowledge; knowledge is empowering in that it creates confidence. If a person has no experience with the situation, they may not know what to expect, alternatively, their expectations may be unrealistic. The nurse should clarify expectations, which provides the chance to identify any knowledge gaps or misconceptions, and assist the patient in setting achievable goals. Nothing is certain in illness, but being informed can increase stability and careful planning can influence the perception of level of control over the situation. The environment influences the ability to cope with transitions by having adequate support networks, including family, friends and community, and access to sufficient and reliable resources (Schumacher & Meleis, 1994). Meleis et al. (2000) described environmental influences as facilitators and inhibitors to the success of transitions, however, they add marginalization and socio-economics among factors that may present barriers to overcoming challenges posed by transitions.

Nurses need to consider all transition patterns in the family's life, rather than focusing solely on the illness. Both the comfort level and ability to cope with change must be assessed. The dynamic nature of transitions necessitates constant re-evaluation with each derailment from the original plan of care. This re-evaluation may be performed by the family unit affected, or may require assistance from external sources and direction toward alternate resources. The focus of transition facilitation is not necessarily curative or return to a disease-free state. In the case of chronic conditions, the focus may relate to re-establishing equilibrium or adapting and developing a new norm.

**Adaptation.** Often the impending birth of a child incites fear and uncertainty in parents,

along with the many joys they experience. When the child is born, a major adjustment is experienced, whether it is the first or the fifth child entering into that family. When parents face a diagnosis of CHD either pre- or post-natally, this adjustment period is further confounded and intensified and can tax coping resources. Feelings of joy are mixed with sadness, attachment is hindered by fear of death, and the need for control is most evident when control feels elusive (Clark & Shandor Miles, 1999; Kolburn & McCubbin, 1996). Feelings of loss of the expected child and the associated grieving process may be triggered, while some parents remain in a “state of chronic sorrow” (Narramore, 2008, p.104). In addition, the inability for a child to articulate their feelings or express discomfort or pain can result in frustration for parents, particularly those who are first time parents who have never had the opportunity to become attuned to their child's cues (Darbyshire, 2003).

The post-surgical ICU experience forces a role adjustment where parents are unable to assume the primary care for their child (Clark & Shandor Miles, 1999). Parents lives lack routine or a sense of normality while they adjust to balancing work and competing family demands. Sleep, nutrition, privacy and control are compromised when living in the hospital. The move to an in-patient unit when their child has stabilized allows the parents to regain some of the control they have lost. They are placed in a private room, a welcome change from the unabashed exposure of the ICU environment. Parents are encouraged to gradually assume some of the care-giving tasks that they will be expected to provide after returning home. Most importantly, less invasive medical monitoring allows for closer and more frequent physical contact between parent and child and increased mobility and freedom to resume the activities the child enjoys.

Meleis et al. (2000) discuss the idea of the “illusiveness of normality” (Meleis et al., 2000,

p.15). After the initial acute phase of diagnosis and treatment, the family returns home and undergoes an adaptation to living with chronic illness through the creation of a new definition of normal for that family. Health status becomes relative to a new baseline for the child with chronic illness. For example, children with chronic illness are more susceptible to acute infections and exacerbation of their illness, resulting in frequent hospitalizations. Recurrent hospital stays become normal and expected for these families (Balling & McCubbin, 2001). The periods where the child suffers less and functions better becomes the baseline. The binary of the health illness dichotomy does not exist for these families, rather, illness is a now part of health and the goal is to maintain an optimal balance in function within the limitations presented by the illness. These experiences are in addition to the expected life transitions the family will go through such as puberty, childbearing, parenting, and bereavement (Brooten et al., 2002). Illness experiences can challenge a person's self-identity and feelings of loss can be difficult to overcome on the journey toward rediscovery (Kralik et al., 2006). A person needs to accept what they have lost and embrace what they have gained anew, a process that requires time and positive reframing and is easier said than done. A literature review by Knafl and Gilliss (2002) revealed that some families find it difficult to normalize their lives and incorporate illness. The initial transition of moving from a health to illness perspective after diagnosis, as well as periods of transition from hospital to home, were associated with the greatest degree of stress and worry for families. Diagnosis was associated with uncertainty and feeling of loss and was experienced as a particularly difficult time for families (Knafl & Gilliss, 2002). Interactions with health care providers can decrease or contribute to stress. It cannot be assumed that transition always goes well, however being aware of the complexities of the psychological processes of adaptation can

allow nurses to provide assistance to patient's and their families in transition and provide the best chance for success through anticipatory and proactive care planning.

McCubbin and McCubbin (1993) define family adaptation as a “process in which families engage in direct responses to the extensive demands of a stressor, and realize that systemic changes are needed within the family unit to restore functional stability and improve family satisfaction and well-being” (in Friedman et al., 2003, p.57). Kralik et al. (2006) believed that awareness of the need for change is followed by a period where the person becomes engaged in activities to work through the change such as seeking information and redefining roles. The authors argue that awareness must proceed engagement and thus awareness directly influences level of engagement. Nurses working with people in transition can facilitate the recognition of the need to work toward adaptive changes in order to encourage more active engagement.

**Uncertainty and meaning.** A family adapting to chronic illness is not merely coping, as that would imply maintaining a status quo; they are developing. This period of adaptation involves managing uncertainty and creating new meanings (Meleis et al., 2000, p.15). Neville (2003) defined uncertainty as “the inability to determine the meaning of illness-related events, assign definite values to objects and events, and/or accurately predict outcomes” (p.206). Michel's (1988) midrange theory of uncertainty in illness describes the cognitive process of constructing meaning out of illness-related events. Within a constructivist metaparadigm, lived experience is reality and meaning is created and dependent upon context; the illness experience is contingent on the meaning the family attributes (Jerrett, 1994). Positive reframing through reevaluating values and appreciating the temporality of life allows for a change in viewing uncertainty as a danger to viewing it as an opportunity (Michel, 1988; Neville, 2003). Education

can assist in providing meaning and context and filling knowledge gaps which contribute to uncertainty. Social support offers a means of clarifying and validating meanings. Often times talking through a situation with a trusted friend brings clarity and reduces uncertainty.

Consistency in health care provider behaviour and accessibility creates a set of expectations that the family can rely on the provider to act as a source of support. Providers can help to normalize a situation through validation of events and clarification of any misconceptions. When coping is successful, it results in adaptation.

Uncertainty is not always associated with negative outcomes; research suggests that moderate uncertainty can have positive effects for some (Wurzbach, 1992). Uncertainty can provide the impetus for information seeking and can be a precursor for maintaining hope in a given situation; it can also be a source of major stress and ambiguity (Neville, 2003). Certainty, on the other hand, may allow predictability of an outcome, and a greater sense of control, but if that outcome is dire, certainty can lead to a loss of hope and feelings of despair. At the opposite extreme, a high degree of uncertainty can induce fears of loss of control, hopelessness, and a lack of conviction in decision making due to the inability to predict outcomes (Wurzbach, 1992).

The nurse can facilitate managing uncertainty through cognitive reframing. According to Wurzbach (1992) “clients are distressed not by things, but by the view that they take of them” (p.32). The nurse should help the family identify collective stressors and their associated meaning. In demonstrating that a stressor can be changed, or at the very least, accepted, the nurse is promoting cognitive control for anticipatory coping (Wurzbach, 1992, p.33).

Congruence between the parents' subjective interpretation of their ability to manage the illness and the expectations health care professionals have of the family can influence the degree to

which families feel supported (Jerrett, 1994). Therefore, it is necessary to clarify expectations and engage in collaborative goal setting. Conflicting information from different health care providers has been shown to increase parental distress and level of uncertainty (Dodgson et al, 2000). The health care team should provide consistent information and education; a team liaison and representative can ensure that all team members are communicating the same information.

**Stress and coping.** Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141). The authors emphasize the distinction between coping and automatic adaptive behaviour in that coping requires some conscious action on the part of the individual. Coping does not necessarily equate with mastery and it can include avoidance, tolerance, or acceptance of the situation.

Emotion-focused coping is aimed at reducing emotional distress and is frequently a result of reappraising a situation, rather than changing the situation itself. However, the authors argue that this is not always the case and avoidance of the situation can be a coping mechanism that does not necessarily results in changing meaning (Lazarus & Folkman, 1984). Problem-focused coping strategies involve identifying the problem and devising solutions which are then acted upon. The authors distinguish problem solving from problem-focused coping in that coping strategies are also directed inward (Lazarus & Folkman, 1984).

Kolburn Svavarsdottir and McCubbin (1996) determined that the most significant stressors for parents of children with a CHD are the many adjustments required in a short period of time and anxiety over associated symptoms (p.208). The uncertain outcomes for their child with CHD resulted in parents reporting higher levels of stress than parents of children with other

chronic illnesses. Parents with other children experienced a greater degree of stress than those where the child with a CHD is the first born (Kolburn Svavarsdottir & McCubbin, 1996). Conflicting caregiver demands may contribute to feelings of added pressures. In pediatric hospital setting where it is a general expectation that a parent or family member will be present with the patient, except in extenuating circumstances, this expectation may impose undue challenges on families, including prolonged absence from work, and can contribute to financial strain while jeopardizing employment. This practice should be questioned via an exploration of the family's ability to provide care in hospital, including consideration of the family's support network.

Although parents with multiple children may feel they are pulled in different directions, they have the advantage of experience. New parents need to contend with all the challenges having a child with a CHD brings, in addition to learning basic parenting skills such as feeding, diapering, and behavioral management, all within a context of uncertainty. A family-centred approach calls for a thorough assessment of the family structure and function including examining the means by which each individual adapts to stressors. Kolburn Svavarsdottir and McCubbin (1996) revealed that the most difficult task for both mothers and fathers was providing support to their partner; fathers reported their supportive role to be the most time consuming of their care-giving tasks. Therefore, any intervention should emphasize parents supporting one another and education should include information on coping measures to aid adaptation through transition. A focus on family strengths and capacities may assist in empowering families to cope with difficult circumstances.

### **Existing Models for Transitional Care and Chronic Care Coordination**

Financial resources are limited, however, it could be argued that by decreasing redundancy and increasing efficiency in patient care, decreasing hospital readmission rates, morbidity and mortality related to chronic illness, and doing so through methods empirically proven to generate cost savings, there are only gains to be had. Two models exist that are applicable to the the care of people with chronic conditions and the care of people with complex needs during the transition between hospital and home. Both the Chronic Care Model and the Transitional Care Model have been through multiple stages of implementation, evaluation, and revision. These models offer a well developed consortium of resources and tools in a structured format for organizations wishing to redesign practice to address the needs of clients with complex care needs. For the pediatric population of patients, elements of each of these models could be incorporated to address gaps in services in transition care and post-discharge follow-up.

**The Chronic Care Model.** The Chronic Care Model (CCM) was conceived in the early 1990's led by Edward Wagner with funding from the Robert Wood Johnson Foundation (RWJF) and was published in 1998 (Wagner et al., 2001). The model was based upon scientific literature by the MacColl Institute for Healthcare Innovation. The model was revised in 2003 to reflect findings from health care systems that had implemented the Model (Improving Chronic Illness Care [ICIC], 2006; Wagner, 2000). The CCM is a system for providing quality chronic disease management and has demonstrated positive health outcomes for patients. The CCM provides an evidence-based framework to guide quality improvement, rather than an explanatory theory.

ICIC (2006) defines a chronic condition as one that “requires ongoing adjustments by the affected person and interactions with the health care system”. Chronic illness is approaching

epidemic proportions and, as such, has created increased demands on health care for which current systems are poorly designed to address. The issues in chronic care management that the model proposes to address include the lack of care coordination, lack of practitioner time, lack of patient follow-up, and lack of patient preparation to engage in self-management. The model takes a preventative approach of maintenance of optimal functioning, rather than a reactive approach of response to illness.

The CCM aims to improve care at the community, organization, practice, and patient levels. According to the CCM, the six essential elements of a health-care system include the community, health care system, self-management support, delivery system design, decision support, and clinical information systems. Within these elements are change concepts which guide practice redesign in each of the six areas. The model diagram is included in Appendix A.

Productive interactions between informed, activated patients and prepared, proactive health care teams is expected to lead to improved functional and clinical outcomes for patients. Informed activated patients have the information and skills necessary to confidently engage in decision-making surrounding their health and its management (Wagner et al., 2000). Health care teams must possess the expertise, time and resources to engage in productive patient interactions (Wagner et al., 2000). The interactions between patients and health care providers are continuous relationships with anticipatory, evidence-based care planned according to individual patient needs (Wagner et al., 2000). The goal is to achieve improved health outcomes for patients, increased satisfaction for care providers, and cost savings to the health care system through detailed patient assessment, self-management support, optimized therapy and follow-up (Wagner et al., 2000).

At the *health systems* level, the goal is to “create a culture, organization and mechanisms that promote safe, high quality care” (ICIC, 2006). This is achieved through supporting quality improvement initiatives and system change. Within the health systems level is delivery system design, decision support, and clinical information systems.

*Delivery system design* entails the “delivery of effective, efficient clinical care and self-management support (ICIC, 2006). According to Wagner et al. (2000) this is achieved by providing clinical case management for complex patients, regular follow-up, and care that is appropriate to the patients level of understanding and cultural background. Team members should have clearly defined roles and equally distributed tasks and engage in structured, planned interactions with patients. *Decision support* relates to practice that is evidence-based and patient-centred. Guidelines for treatment must be developed based on the most current clinical research and care providers must remain current in their knowledge. *Clinical information systems* involves the utilization of “patient and population data to facilitate efficient and effective care” (ICIC, 2006). It entails creating and maintaining a patient registry used by the entire care team to track treatment and progress. Using patient and population data assists in the identification of patients most at risk for poor health outcomes in order to provide proactive and preventative interventions. Program evaluation should be integrated into practice redesign in order to ensure internal monitoring of program performance. In addition, clinical information systems can be useful in providing reminder systems for patient services to ensure continuity of care. Technology can be utilized for the convenience of patients so that not all visits need to take place face-to-face. Telephone and video conferencing can be used for consultations between patients and care providers, allowing for more cost-efficient follow-up and convenience.

*Health systems* overlap with the *community* in the CCM model, as the health care team links the patients with community resources essential to their care. Care providers should be knowledgeable of community resources available to their patients and readily refer in order to avoid duplication in services. In addition, looking outside the health care system includes advocating for the creation of health policies at the government level to support patients with disabilities and chronic health conditions.

Once in the community, patients are required to engage in self-management of their illness. With children, self-management is limited by the dependency on parents who are the ones engaged in managing the condition. Health care providers must empower families to manage their health care through emphasizing patient and family strengths, engaging in goal-setting, planning, and assisting with problem-solving (Wagner et al., 2000). This collaborative effort builds parents skills to independently manage similar situations in the future.

When implementing the CCM, the intention is to build an entirely new system, rather than scaffold onto a system that cannot support the management of chronic illness care. Wagner et al. (2000) state that “improvements in care cannot be achieved by further stressing current systems of care” (p.65). The U.S.-based national initiative for Improving Chronic Care through the implementation of the CCM provides a variety of tools that practitioners can utilize to engage in practice redesign initiatives (ICIC, 2006). They offer a quality improvement evaluation program in collaboration with the Institute for Healthcare Improvement, support and technical assistance for organizations engaging in practice change following the CCM guidelines for improvement, and provide grants to researchers investigating chronic illness management (ICIC, 2006; Institute for Healthcare Improvement [IHI], n.d.). For example, tools are available from both websites to

assess the current state of chronic illness care within an organization and identify areas in which redesign should be focused within each of the 6 CCM domains. In addition, the ICIC website offers chronicles of the experiences of teams who have successfully integrated the CCM model into their practice. Both websites also offer information and resources for using the Model for Improvement to guide system redesign and a series of tools to utilize the PDSA cycles, a component of the Model for Improvement. In addition, resources are available to health care providers to be able to coach and support patients in self-management. The ICIC website also provides resources on health literacy and readability.

***Evidence of model benefits.*** As a condition of the authorization of the model, the RWJF mandated an independent evaluation of the implementation of the model. This evaluation was conducted over a four year period, across 51 participating sites, involving approximately 4,000 patients. The results demonstrated that change was successfully enacted in 5.8 of the 6 CCM areas. Patients had a decreased risk to developing co-morbidities commonly associated with their conditions and demonstrated increased knowledge about their condition, length of hospital stays decreased, and therapy compliance increased. Most importantly, a one-year follow-up to the study revealed that “82% of the sites had sustained the changes and 79% of sites had spread change to other places or diseases” (ICIC, 2006).

Wagner et al. (2000) examined the use of CCM for a variety of chronic diseases across multiple care systems. A study of 104 health care organizations who implemented the CCM to improve care related to a single chronic condition confirmed that CCM can be used to guide practice change across systems of varying size and financial structures. In addition, the authors confirmed that comprehensive systems change is necessary to provide effective chronic illness

management; small scale enhancements did not produce significant outcomes. This could present a barrier for many organizations in adopting this model of change as fiscal and human resources may not be available to implement change on such a grand scale. Leadership support was an essential ingredient to successful change as more senior leaders could help navigate around barriers to improvement initiatives. Forming effective partnerships with community services was a cost-effective methods of accessing services and reducing duplication, particularly for smaller organizations. The greatest barrier to change was economic, with reimbursement policies restricting payment to care providers for services not rendered face-to-face, group interactions, and support or coaching for self-management, all essential elements of the CCM.

Tsai, Morton, Mangione, and Keeler (2005) conducted a meta-analysis of 112 studies of interventions to improve care for chronic illnesses. The authors found that interventions which incorporated one or more CCM elements lead to improved clinical outcomes and processes of care (p.485). Their analysis examined the four elements of the CCM of delivery system design, self-management support, decision support, and clinical information systems; community resources and health care organizations elements were not represented by a sufficient number of studies in the sample to provide evidence of effectiveness. The authors could not determine which elements of the model produced the greatest impact on quality of life for patients, however, they reported stronger effects for delivery system design and self-management support with decision support demonstrating benefits on processes. Although the CCM is designed to be implemented as part of a large scale system redesign, and Wagner et al. (2000) argue that without a holistic approach to changing systems of chronic care management desired outcomes will not be achieved, Tsai et al. (2005) found that single interventions were successful. However, the

authors caution that the studies in their sample only incorporated certain CCM elements, rather than the entire package, thus limiting comparison to complete system redesign.

Bodenheimer, Wagner, and Grumbach (2002) performed a systematic literature review of diabetes care programs featuring elements of the CCM. Similar to the literature reviewed by Tsai et al. (2005), the literature sample for this review focused on the only four elements of CCM, excluding health care organization and community resources. A total of 39 studies involving 200 practices were included in the review. The results indicated that the CCM-based intervention improved a minimum of one process or outcome measure in 32 of the 39 studies. The authors were unable to conclude if the use of multiple CCM elements resulted in better outcomes than use of a single component, nor were they able to distinguish a single most effective element. Bodenheimer et al. (2002) concluded that visionary leaders are required to successfully implement the system redesign required for the CCM to be effective, and finances must be made available to assist with implementing the change. According to the authors, in absence of the ability to implement the model using all the elements, practices that implement portions of the model will produce benefit for themselves and their patients.

Although the number of studies reviewed that reported positive cost reduction outcomes outweighed the studies for which this finding was negative, Bodenheimer et al. (2002) were unable to definitively demonstrate cost-reduction outcomes as a result of the CCM interventions. However, the results of multiple studies that were positive for reduced health care costs suggest self-management support as a potential contributing factor. More research is needed to explore this possible connection. In addition, research should focus on the cost savings of long-term programs, as the authors believe that the benefits of temporary programs may be short-lived. A

limitation of this review is that it deals with only one chronic illness. The majority of people with chronic illness suffer from more than one condition, therefore research is needed to determine the effectiveness of the CCM interventions on clients with multiple chronic conditions.

**The Transitional Care Model.** Dr. Naylor and colleagues have developed a model for transitional care that has been extensively applied and tested in practice over the last 20 years. Testing has demonstrated significant positive outcomes for patients including improved satisfaction with care, reduced re-hospitalizations, and reduced overall health care costs. The framework acts as a bridge in care for vulnerable patients being discharged from hospital to home. The goal of the model is to “promote early discharge of high-risk, high-cost, high-volume groups of patients by substituting a portion of hospitalization with a comprehensive program of transitional care” (Brooten et al., 2002, p.370). This is achieved through comprehensive discharge planning and home follow-up individually designed to suit patient's requirements (Brooten et al., 2002; Naylor et al., 1999). Care is coordinated to ensure continuity and health complications are minimized or avoided through close clinical management, interdisciplinary communication, and patient / care-giver education and support provided by a Master's prepared nurse as primary care coordinator.

The model encourages a holistic focus on patient's goals and needs for all health issues, engagement of patient and care-givers, and development of individualized, evidence-based care plans (Transitional Care Model [TCM], 2008). Use of the model results in early identification and response to health care risks and symptoms. This anticipatory approach to care improved long-term positive outcomes, and decreased hospital readmissions (TCM, 2008).

The protocol that was used in initial research on the implementation of this service guided the assessment and management of patients over a specific number of visits from the transitional care nurse, an advanced practice nurse (APN) with expertise in transitions. According to Naylor et al. (1999), the initial nurse contact with a patient was made within 48 hours of hospital admission. It is not clear what method of referral was employed, or if active recruitment was performed. Subsequent visits were conducted a minimum of every 48 hours during the duration of the patient's hospitalization. Post-discharge, a minimum of two home visits were conducted; the first within 48 hours of discharge with a second seven to ten days post-discharge. Additional visits were based on individual patient need with no set limits (p.614). In addition, a nurse was available by phone seven days a week within specified hours. The nurse initiated phone contact with patients/caregivers on a weekly basis for further follow up.

***The dimensions of the transitional care nurse role.*** In order to develop programs and measure performance outcomes for services it is necessary to determine what specific issues the patient population of focus most frequently experiences and the nature and extent of services they require. Naylor et al. (1999) conducted a randomized control trial in order to examine the effectiveness of the TCM intervention for elders at risk of hospital readmission. In the hospital, transitional care nurse interventions included initial assessment of the nature and severity of health problems, physical and cognitive function, and psycho-social health. Discharge goals for the patient were established and social support, knowledge, and skill gaps were determined. A secondary analysis of patient records during the initial randomized control study was performed by Naylor, Bowles and Brooten (2000) in order to determine the most frequent needs of elderly patients during transition and the most common nursing interventions performed in transitional

care, according to the TCM protocol. Hospital-based interventions were documented from hospital admission to 1 month post-discharge and were divided into categories of surveillance, case management, teaching/guidance and counselling, and treatments or procedures.

Surveillance activities included monitoring or observing for physical signs and symptoms, medication set-up and administration, mobility and transfers, mental and emotional signs and symptoms, nutrition, and the home environment. Case management activities included communication with the interdisciplinary team and with patients and family, medical care coordination, medication set-up and administration, accessing lab findings, managing physical signs and symptoms, medication actions and side effects, coordinating nursing care, finances, and referral / connection to community resources. Teaching, guidance, and counselling was related to medication actions and side effects, mobility and transfers, physical signs and symptoms, medication administration, nutrition, sickness, injury care, medical care, cardiac care, bronchial hygiene, safety, and anatomy/physiology (Naylor et al., 2000). Roughly two-thirds of the interventions were of a surveillance nature. The remaining nursing interventions were divided with a similar distribution between teaching/guidance and counselling (20%) and case management (14%) with minimal time required for treatment/procedure intervention (Naylor et al., 2000, p.100). Interventions in the home included services related to medications, symptom management, diet, activity, sleep, medical follow-up, and psycho-social support (Naylor et al., 1999, p.615).

Although this model was designed to care for high-risk older adults, a pediatric population might experience many similar issues identified in the elderly patient population. Additional concerns might include surveillance and education related to attachment and parenting, assessing

and addressing issues with behavioural and cognitive development, teaching developmentally appropriate coping skills, and assessing for signs and symptoms using non-verbal means.

A similar study to those done on elderly populations compared common issues among a variety of patient groups and the type and frequency of nursing interventions under the TCM protocol (Brooten, Youngblut, Deatruck, Naylor & York, 2003). The study population most closely related to the pediatric population of focus for this paper was very low birth weight infants (VLBW). The most frequent issues this population and their caregivers faced were environmental problems including income and residence, psychosocial problems including caretaking/parenting, health care supervision, and issues related to growth and development. Physiologic concerns were related to the following systems: respiratory, integument, digestion/hydration, and bowel function (Brooten et al., 2003, p.76).

The most frequently provided interventions for this patient population were surveillance activities. These activities consumed 62.3% of the transitional care nurse's time and included services pertaining to observing caretaking/parenting ability, signs and symptoms, physical environment (in the home), and nutrition. Case management activities were the second most frequent consuming 24.9% of nursing time and included interdisciplinary communication and medical/dental care-coordination. Health teaching, guidance and counselling took up 12.5% of nursing time and included education extending from surveillance of care-taking/parenting ability, nutrition, sickness/injury care, and sign and symptoms. The least frequently provided service was clinical treatments and procedures at 0.2% of nursing time (Brooten et al., 2003, p.77). These procedural tasks were likely delegated to primary nurses while the transitional care nurse was focused on providing services of a holistic nature that require coordination and

communication beyond that for which the bedside nurse typically has time for in a task-oriented medical model of care. These findings displayed a similar pattern of patient needs and nature of services to those found in studies on elderly patients.

***Evidence of model benefits.*** In the randomized control study exploring the effect of the TCM intervention on elderly patients, Naylor et al. (1999) used outcome measures of hospital readmissions, recurrence/exacerbation of condition, co-morbid conditions, and new health issues. Secondary outcomes measured included cumulative days of re-hospitalization, mean readmission length of stay, number of unscheduled acute care visits after discharge, estimated cost of post-index hospitalization health service, functional status, depression, and patient satisfactions (p.616). The authors concluded that TCM intervention reduced hospital readmission, lengthened time to first readmission, and decreased overall cost of care. Naylor et al. (1999) believed a major contributing factor to the success of the program was a holistic focus on the combination of health and social issues rather than on a single diagnosis. Functional status for the intervention group did not improve, consistent with previous studies examining discharge planning and home care, nor was there any statistically significant difference in depression scores or patient satisfaction levels (patient satisfaction was high in both groups). The authors estimated that savings to medicare over a six month period amounted to \$600,000 for 177 in the intervention group, or \$3000 mean per person (p.620). Of note is the finding that the number of home care visits between intervention and control groups did not differ significantly, despite the fact that number of home visits were unlimited for the intervention group. This could perhaps be attributed to the availability of the transitional care nurse by phone. This study highlights the outcomes measures of importance to consider when planning evaluation of services implemented

under the TCM framework.

In a study by Brooten et al. (2002), the authors found that interventions without home visits resulted in more re-hospitalizations than when home visits were added to the intervention and that the effects of home visiting were maximized if the home visit was done within 24-48 hours after discharge from hospital. The authors recommended that patients in need of transitional care coordination be identified early on in order to expedite discharge while making sure all necessary services are provided in a timely fashion. In addition, when planning discharge, the authors stress the importance of starting teaching early to ensure opportunity for repetition of information and time for return demonstration by patients and their caregivers.

An additional study by Brooten et al. (2003) demonstrated there was an APN “dose effect”. In comparing different patient groups and the APN interventions they received, the greater the mean APN time per contact and number of overall contacts per patient resulted in better patient outcomes and increased health care cost savings.

The studies done on the implementation of the TCM to date provide valuable quantitative evidence for the efficacy of the program which is essential when presenting a practice redesign proposal to key stakeholders. Despite the fact this model has been tried and tested over a 20 year period, there remain areas for future research. Brooten et al. (2003) suggest the model should be tested with APNs acting in a supervisory capacity, rather than performing direct clinical care. In addition, the model should be tested with other vulnerable patient groups that experience frequent hospitalizations, re-hospitalizations, or high health care costs. There is little evidence available in the literature for use of this model in pediatric populations, indicating a need for further research among this patient population.

### **Marrying the Models**

The CCM provides an established program of education and resources to assist and support clinical practice redesign and quality improvement initiatives at the systems level. The objective is to increase efficiency, augment follow-up, and improve patient outcomes. Clinical information systems and decision support are incorporated as delivery system aids within the health system. The TCM provides a framework for care delivery within the system which guides the actions and interventions of the APN leading the transitional care team in productive interactions with the patient. The transitional care nurse acts as the link between the patient, health system, and community. The APN, as an extension of the health system, interacts with the community to link the patient with resources external to the hospital and facilitates the acquisition of patient self-management skills. Therefore, CCM can be considered the guide for program conception, implementation and evaluation, while the TCM guides the care delivery component of the program itself.

### **Health Literacy**

**Definition of health literacy.** In developing new program or services to meet patient needs, health literacy issues must be a central concern surrounding knowledge transfer between health care professionals and patients/families. The Health and Learning Knowledge Centre (HLKC) define health literacy as “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” (HLKC, 2008, p.3). Murray, Rudd, Kirsch, Yamamoto, and Grenier (2007) offered a similar definition but include the ability to “make appropriate health decisions” (p.4). Murray et al. (2007) described that the commonality among varying definitions of health literacy is in the

emphasis on individual skills related to “processing and understanding basic health information” in making health related decisions (p.11).

Even those with strong reading and writing skills can have difficulty understanding health related information. Unfamiliar medical terminology or a lack of awareness about body mechanisms can contribute to difficulty understanding medical information (Centres for Disease Control, 2010). In addition, the emotion involved in receiving diagnoses can overwhelm a person's ability to think critically or retain information. Complex care plans can be challenging to follow even for those with high literacy levels and contact with multiple care providers or a lack of interdisciplinary communication creates challenges in providing consistent care (Canadian Public Health Association [CPHA], 2006).

In addition to affecting communication between health care provider and client, health literacy affects ability to read and comprehend, follow instructions, analyze information, weigh risks and benefits, take medications as directed, provide informed consent, or provide an accurate and thorough patient history (National Institutes of Health [NIH], n.d.). The skills needed for health literacy that differ from basic reading proficiency include the ability to evaluate information for credibility and quality, analyze risks and benefits of treatments, locate health information or operate a computer and navigate the internet, interpret and apply findings from graphs or tables, understand figures of risk, and perform basic mathematical skills such as dosage calculations (Glassman, 2010). Evidently, health literacy encompasses the need to incorporate prose, document and numeracy simultaneously (Canadian Council on Learning [CCL], 2008).

**Prevalence of low health literacy.** Low health literacy is approaching epidemic proportions in Canada. In 2007, approximately 60% of Canadians aged 16-65 lacked the

minimum level of health literacy needed to effectively manage their health information needs (CCL, 2008; HLKC, 2008, p.4; Murray, Hagey, Willms, Shillington, & Desjardins, 2008). In addition, literacy levels show a decreasing trend with age, therefore in factoring seniors into the statistics, 88% of the population has a level of literacy below functional for health information needs (HKLC, 2008, p.4). Canadians have higher levels of literacy than the United States, but in North America, males have lower levels than females. Low health literacy is most prevalent among older adults, minority populations or immigrant groups, those with low socio-economic status, the underemployed and people with chronic mental and/or physical conditions (CCL, 2008; CPHA, 2006; Health Resources and Services Administration [HRSA], n.d.; Murray et al., 2008). Levels of low health literacy (60%) are higher than levels of low prose literacy (48%) in Canada, reflective of the increased complexity of health literacy over basic literacy (Murray et al., 2008).

Level 3 is considered the minimum level required to manage health needs and is equivalent to high school completion (HKLC, 2008). In 2007, 55% of Canadians fell below literacy level 3 according to the Adult Literacy and Life Skills Survey (Murray et al., 2007, p.23). Level 3 includes the ability to integrate information from more lengthy text, integrate multiple pieces of information, understand mathematical information in different forms, and complete tasks that require multiple problem solving steps (Murray et al., 2008, p.13). Level 2 includes the ability to distinguish between reliable and unreliable sources of information, integrate two or more pieces of information, compare and contrast information, and interpret simple graphs (Murray et al., 2008, p.13). Level 1 includes the ability to read short text, locate information, and complete tasks that require a single step such as counting or simple arithmetic

(Murray et al., 2008, p.13). Clearly, the scope of information integration required for health literacy requires a minimum of level 3, however, those with level 4 or 5 literacy are much better situated to take charge of their own health.

**Implications of low health literacy for health and well-being.** The implications of low health literacy are many and results in an increased cost to our health care system. According to the Public Health Agency of Canada (2005) examples of direct effects of low health literacy may include accidents caused by misunderstanding warning labels and caution messages, injury due to failure to understand directions for use of potentially dangerous equipments in the home or workplace, illness caused by misreading medications, or health risks to infants from misreading directions for formula preparation. Indirect effects may include working and living conditions that have higher health and safety risks, poor decision making surrounding personal health practices and life and coping skills, and limited access to health information and services.

The CPHA (2006) defined chronic disease as “any physical condition associated with a decrease in health lasting more than six months, and for which contact had been made with one or more health care professionals” (p.2). Chronic diseases, the leading causes of death in Canada, contribute to more than 75% of all deaths (CPHA, 2006, p.2). Certain populations are more vulnerable to chronic illness as seen among lower income earners, Aboriginal peoples, ethnic minorities, and single parent families (CPHA, 2006). These same populations are at highest risk for literacy challenges. Of those with inadequate and marginal health literacy levels 50% had a higher mortality rate over a five-year period than those with adequate skills (CPHA, 2008, p.6). By educating people on changing health behaviours such as diet, physical activity, and substance use, they can reduce their risk of developing chronic disease (CPHA, 2006, p.4).

Educational achievement is the second strongest factor in literacy proficiency (Murray et al., 2008, p.26). Level of education achieved predicts levels of literacy and increasing age amplifies the education-based inequalities (Murray et al., 2007, p.6). Higher levels of educational achievement have been linked to better health therefore, health literacy is considered a critical causal factor for health outcomes (Murray et al., 2007). In fact, according to the CCL (2008), Canadians with lowest literacy skills are 2.5 times more likely to report fair or poor health compared with those of higher literacy ability. The Canadian Literacy and Learning Network (Canadian Literacy and Learning Network [CLLN], n.d.) states that poor health and other socio-economic factors are barriers to learning. Therefore, if certain factors predispose an individual to be of low literacy, it could result in poor choices regarding health and lifestyle behaviours, combined with poor environmental conditions secondary to economic factors, such as inadequate and unsafe housing. Poor health, however, creates a barrier to learning, making it difficult for the individual to overcome literacy challenges.

**Families and literacy.** Literacy begins in early childhood (CPHA, 2008). The skills and capacities developed before the age of 6 are thought to stay with us for life (CLLN, n.d.). Research has demonstrated that children have a better chance of becoming fully literate adults if readings is encouraged in the home (ABC Life Literacy Canada, n.d.). Not only does reading to a child develop a sense of attachment to the parent, which is believed to contribute to feelings of security and self-worth, but children who are read to daily have demonstrated improved academic performance over peers who are not read to regularly in childhood (ABC Life Literacy Canada, n.d.). Therefore, as nurses, we need to set a positive example for children and encourage parents to read with their children often. Providing recommendations and resources

for parents to improve their own literacy skills can have a direct impact on the language and literacy development of children. According to Murray et al. (2008), scores on literacy tests for those who engaged in daily reading were significantly higher than for those who do not. In addition, the authors found that normal decline in brain function due to ageing can be slowed through continued learning (p.29). Establishing a culture of learning and encouraging an exchange of ideas, can strengthen relationships between families and care providers and empower families through confidence building and independent decision making.

**Recommendations for overcoming health literacy barriers.** According to the CPHA (2006), self-management includes taking medications as prescribed, refilling prescriptions, making follow-up appointments with care providers and scheduling lab tests, using monitoring devices such as blood pressure monitors or blood glucose monitors, adhering to diet restrictions, following recommendations for exercise and other lifestyle modifications, being able to track symptoms and relay a history to the physician, and the ability to access resources available in the community. Patient self-management has been promoted as one way to approach care of clients with chronic disease, however, low literacy is a barrier to effective self-management (HLKC, 2008, p.16). In fact, the Health and Learning Knowledge Centre cited a review of randomized control studies which demonstrated that of patients with lower literacy levels, “62% were unable or unwilling to engage in self-management” (HLKC, 2008, p.16). Therefore, improving literacy may improve self-management. Murray et al. (2007) suggest that efforts to raise health literacy levels may be a low-cost method of improving health outcomes and self-management. The authors argue that improving health literacy may also lead to reduction in duration of treatment, hence decreasing cost of treatment.

Cultural and language barriers contribute to low health literacy, therefore service providers who do not adjust language for the lay population, or provide culturally sensitive care, also contribute to health literacy issues. If possible, it is best to provide written material in the client's primary language and assist clients in completing forms as necessary (HRSA, n.d.). The NIH (n.d.) Clear Communication Initiative focuses on providing information that is accessible to those with cultural and language barriers and incorporating plain language approaches targeted for audiences with limited literacy. Their website offers a variety of health literacy resources for health care practitioners. Tools exist to assist with assessing health literacy, developing materials tailored to those with lower literacy levels, evaluating readability, engaging in effective communication to ensure comprehension of information, and resources for policy makers. NIH is conducting important research in several areas related to health literacy including exploring the relationship between health literacy and healthy behaviours, illness prevention and treatments, chronic disease management, health disparities, and health outcomes.

The HRSA (n.d.) suggest that health care providers assess individual literacy level, use simple language, and utilize visual materials to supplement verbal instructions, such as diagrams or videos. Highlighting key points in a summary of a conversation followed by asking open-ended questions, or having clients teach the information back to the provider, are effective techniques to test for retention and understanding.

North Carolina Program on Health Literacy (2011) recommends the need to increase awareness of the issue of low literacy and aim to improve knowledge and skills of health care professionals in assisting clients to understand and be involved in decision making. They advocate for basing services on evidence-based models for communicating health related

information to people with low literacy levels. In addition, they also stress the need to provide health care communications tailored to those with low literacy levels.

The CPHA (2006) advise that health care providers work to narrow the gap between the literacy demands of the system and literacy skills of the patients (p.8). The Chronic Care Model is based on productive interactions between the patient and health service providers. Health literacy can present a barrier to the productivity of these interactions if health care providers do not strive to reduce inequities in health literacy and tailor education, information sharing, and engaging in shared decision making, to the literacy level of the client. The CCM relies on informed patients, trained well-prepared health service providers. Health service providers have a responsibility to ensure patients are truly informed and understand the full extent of the information provided and to do so must be knowledgeable about the issue of health literacy and possess an understanding of how to overcome barriers related to low literacy levels. Limited health literacy affects interactions between patient and provider, and hence, the patient and the health system (CPHA, 2006, p.9).

The HLKC (2008) advocate for the need to develop a national strategy on health literacy focused on reducing inequities in health literacy among individuals, enhancing individual capacity, making services appropriate for the level of health literacy that is most prevalent, and increasing support available to effectively deal with health literacy demands.

**Part III: Locating the Issue Within Advanced Practice Nursing**

**APN Leadership**

TCC is most appropriately provided under the leadership of a clinical nurse specialist (CNS) because it necessitates clinical expertise in providing direct client care; expert guidance and coaching; consultation; interdisciplinary, intraprofessional and nurse-client collaboration; clinical, professional and systems leadership; research and scholarly inquiry; and ethical decision making. According to Hamric et al. (2009), these characteristics make up the seven core competencies of APN that are executed in a CNS role (p.83). The Canadian Nurses Association (CNA) has also developed an APN Framework depicting four core competencies expected of an APN, similar to those of Hamric et al. (CNA, 2008). The APN provides expert specialization for complex, unpredictable patient populations with intensive care needs, integrating theory and research-based practical knowledge with a higher level of critical thinking and analysis.

According to Bryant-Lukosius, DiCenso, Browne and Pinelli (2004), issues that influence APN role development, implementation and evaluation include confusion about the role stemming from inconsistent terminology and educational preparation, a “lack of clearly defined role expectations, emphasis on physician replacement and support, under-utilization of the full scope of APN role domains, environmental factors that undermine APN roles, and limited use of research and evidence-based approaches to guide the introduction of new APN roles” (p.520). Inconsistencies in national educational preparation for APNs, and lack of standardized credentialing, obscure attempts to create a common understanding of APN practice. Continuing to empirically validate the impact of APN care on patient outcomes and health care costs is essential.

CNS practice impacts three spheres of influence: direct patient care, nursing profession

and practice, and systems or organizations (Hamric et al., 2009, p.354). Leadership at the advanced practice level draws upon knowledge and skills from four domains, similar to the spheres of influence of a CNS, and include clinical leadership, professional leadership, systems leadership, and health policy leadership. A CNS working toward establishing a TCC program works across the first three domains, exclusive of the health policy domain (Hamric et al., 2009).

Direct client care is central to CNS practice, therefore, represents the primary sphere of influence. Clinical leadership focuses on patient needs and delivery of quality care. A CNS impacts the clinical leadership domain by working with patients and families as a coach, collaborator, advocate, and resource person. The CNS helps the patient/family navigate the medical system. A CNS works as a liaison between the interdisciplinary team, facilitating collaboration and arranging team and family meetings when necessary. When necessary, the CNS can consult external resources on the family's behalf. The CNS with advanced communication skills will be most successful in demonstrating these leadership qualities and fulfilling leadership demands. Coaching is a core component of a TCC program. Donner and Wheeler (2009) believed that the relationship between a coach and the family is a collaborative one where the family is acknowledged as the expert on the subject of their child, and their life.

Influence on the nursing practice sphere is demonstrated through mentoring, coaching, intra-professional collaboration, research, consultation and role modeling. Similarly, leadership in the professional domain is demonstrated through the CNS's advanced interpersonal and negotiation skills, mentoring, leading a group, motivating, and empowering others (Brooten et al., 2002; Hamric et al., 2009). A CNS can coach other nurses in the course of their professional development through communication and relationship building. Mentoring is more formal and

involves a longer-term commitment than coaching, yet utilizes coaching skills to support the professional development of the individual (Donner & Wheeler, 2009). Consultation is another area of leadership exercised within the professional domain. The CNS is an expert in their area of practice and may be consulted to provide educational support for other members of the health care team. A CNS may also be consulted to assist in cases requiring a high degree of liaison work and case management. In addition, the CNS has advanced educational preparation in ethics, and as such, may be called upon to consult in situations requiring ethical decision making, such as end of life care.

The systems sphere is influenced through patient advocacy, interprofessional collaboration, facilitating and managing change, problem solving, and evaluating outcomes (CNA, 2008; Hamric et al., 2009, p.354). Creating initiatives to address patient needs and improve care, such the initiation of a TCC program, requires systems leadership. Hamric et al. (2009) described leaders who “create new opportunities to exercise their special abilities” (p.252). They referred to this as entrepreneurial leadership which requires innovation and risk taking. When the entrepreneurial leader works within and is responsible to an organization, as opposed to an independent practice, the term of reference used is intrapreneur (Hamric et al., 2009, p.252). According to the authors, the entrepreneurial leader must possess the following personal characteristics: “confident, team player, persistent, innovative, risk taker, adjusts to change, decisive, strategic thinker, high integrity, and possesses vision” (p.252). However, it could be considered that these characteristics are not limited to the leadership competency of CNS', rather they are characteristics representative of the CNS in general. An additional example of systems leadership can be found in demonstrating accountability and cost-effectiveness

through research and outcome evaluations. CNS leadership at the systems level can also include the initiation of interdisciplinary team meetings to ensure patient care is well coordinated, or forming a committee to identify and address issues and gaps in service on the hospital unit. The CNS as a TCC can base discharge planning on acute care visit data, re-hospitalization profiles, and post-discharge outcomes and create policies and procedures based on this data to ensure care is research-based.

**Defining characteristics of CNS leadership.** Effective leaders are guided by their vision, which they are clearly able to articulate, inspiring in others a desire to achieve mutual goals (Yoder-Wise & Kowalski, 2006). Quaid, Thao, and Denham (2010) refer to this as “communicating the destination [rather] than the specific tactics and course to be taken” (p.9). A successful leader has the confidence to take risks to achieve their vision, knowing that some attempts may fail (Beauman, 2006). This type of *transformational leadership* is the hallmark of a successful change agent (Hamric et al., 2009, p.254; Taylor, 2009, p.43). This may require creative or innovative methods and a keen sense of timing; one must “know when to act and when to hold back” (Hamric et al., 2009, p.264).

A CNS working within the three leadership domains will be most successful when they embody the three defining characteristics of the leadership competency as described by Hamric et al. (2009). These are mentoring and empowerment, innovation and change agency, and political activism (p.260). In developing a new program, the leader selects a team that will work together to make their vision a reality. The leader must mentor the team through the process. The leader's primary goal is to improve the quality of care for the patient population. At the same time, the leader must help the team to learn and develop as professionals. An CNS does not have

to be in a position of power or authority to influence or lead people (Beauman, 2006). By sharing their knowledge and experience, and being a role model for others, the CNS can gain credibility and respect. In the current political climate, the challenge is to create a desirable practice environment in situation of minimal resources (Gurzick & Kesten, 2010).

The language used to describe the professional dynamics of leaders and those they lead can be problematic. Some of the leadership literature uses the terms *leaders* and *followers*. It may be more appropriate to refer to *leaders* and *teams* because the use of the term *follower* is dis-empowering and counterproductive to the sharing of power that is fostered by visionary leaders (Hamric et al., 2009). *Followers* does not denote a group of people who are “competent, responsible, independent and authorized to act” (Hamric et al., 2009, p.262). *Followers* describes a group of people waiting for direction who adhere to the beliefs and opinions of a leader without individual thought. Avoiding power dynamics by allowing team members to feel respected and valued as equal contributors can enhance motivation and satisfaction in the workplace.

The most pervasive barrier to clinical practice redesign is resistance to change. According to Dickinson (2002), “even in highly innovative and progressive organizations, 90% of the effort is spent talking about change or convincing people to change, and only 10% is devoted to actually working on the change” (p.2). A leader in redesign must be an effective change agent, drawing upon change theories and equipping themselves with tools to combat barriers to change. Hibberd and Smith (2006) suggest that leaders represent change as “an opportunity rather than a threat” (p.560). A CNS is a change agent; they build successful teams, deal with team conflict, pioneer change, and manage resistance to change (Hibberd & Smith, 2006). Building a team and initiating change requires courage and ambition. The CNS must establish and maintain

credibility; clinical expertise, collaborative practice, and networking skills help establish credibility. The CNS must market their skills as well as the benefits of the program they create. They must seek and retain an effective team who can assist in overcoming resistance to change within the organization. The environment can either support or hinder the move toward change. When cost-constraint measures create competing systems demands, organizations may place priority on assigning a CNS to duties that neglect to focus on direct patient care (Hamric et al., 2009, p.367). However, the clinical component of CNS care is integral to the role, therefore, the CNS must advocate for an appropriate balance between clinical and non-clinical functions when negotiating role creation or challenging the capacity of existing roles.

Political activism is an inherent part of advocating for system change to meet patient needs (CNA, 2009). Shirey (2008) asserted that the CNS should actively pursue involvement in program planning sessions among organizational leaders, rather than wait to be included in the discussions. As a patient advocate, the CNS should be present during budgetary decision-making to ensure appropriate interventions are considered. The CNS can bring the clinical perspective back to the boardroom and provide research-based evidence to strengthen the validity of their requests or opinions. Being an APN leader means “push[ing] the boundaries of practice to innovative new levels” (CNA, 2009, p.1).

**Developing the leader within.** While many transformational leaders can be described as having charismatic personalities, leaders are generally not born but are created through a willingness to learn leadership skills, develop their talents, and build coalitions with others (Yoder-Wise & Kowalski, 2006). Such leaders not only learn their own strengths and limitations, but also those of team members in order to use each member’s talents to the utmost

and create partnerships that cancel out the limitations. McBride believed that “using others effectively is another form of being effective yourself” (Yoder-Wise & Kowalski, 2006, p. 210).

Challenging individual assumptions is an inherent component of self-awareness. Self-reflection is an essential to CNS practice because examining values and beliefs can reveal how emotions may influence interpretation of events or judgments the CNS might be predisposed to form (HCLABC, 2008a). Through self-reflection, education and experience a CNS can evolve the interpersonal skills needed to coach families through life transitions (Hamric, 2009, p.176). Reflecting on professional relationships and identifying areas of concern are essential to becoming a transformational leader (Taylor, 2009).

Leaders for Life (HCLABC, 2008a) conducted an extensive review of the leadership literature and devised a framework for leadership growth. According to this framework, a leader must align their true values with their leadership principles. A leader must exercise emotional restraint and demonstrate positive thinking. A leader must commit to develop oneself through a commitment to life-long learning, including a self assessment of their learning style and learning needs. Finally, by emulating those with high moral character, and acting with consistency and integrity, an individual demonstrates leadership ability.

The Leaders for Life leadership and Management System (LEADS) is extremely useful for developing the leadership capabilities of a CNS (HCLABC, 2008a). The program, designed with the needs of the health care system in mind, consists of five components: leads self; engage others; achieve results; develop coalitions; and systems transformation. The framework can guide the CNS in developing the skills necessary for critical self-reflection, effective communication and collaboration, team building, coaching and mentoring, working with

conflict, and initiating system change. The LEADS system is flexible enough to accommodate leadership appropriate to the context of the organization and the level of leadership required. The CNS can adopt this educational framework for their individual professional development, or work at the organizational level to integrate the program to train leaders poised to transform systems that meet current and future needs (HCLABC, 2008b, p5).

The CNS must be familiar with a variety of theories and models, and utilize those most compatible to the situational context. In addition to the LEADS system, there are several other theories the CNS may find useful to guide the development of individual leadership style or characteristics. These include trait theories, situational-contingency theories, or transactional/transformational theories (Hibberd & Smith, 2006; Taylor, 2009). A CNS can assess the various theories to determine the best fit for their personality, communication style, work environment, and to assist the development of the vision of the leader they wish to become. The CNS applying leadership theory in practice must be skilled at evaluating and analyzing theory content for relevance. For example, Bridges' Transitional Theory of Change helps a leader deal with the anticipated emotional impact of those experiencing change but is not prescriptive with *how* to implement change (Hibberd & Smith, 2006). The Values-Centred Leadership Model (Secretan) may be beneficial in effecting change in an organization where there is a need to build the team to be more positive and functional, but not necessarily useful to lead a team for a specific goal-oriented purpose, such as implementing a new patient care delivery program (Hamric et al., 2009). Developing personal leadership skills and learning how to effectively empower people can be learned through theories such as the Fifth Discipline (Senge) and the Seven Habits of Highly Effective People (Covey). In implementing a TCC program, the CNS

may initially draw upon Diffusion of Innovation in Service Organizations, the conceptual model by Greenhalgh et al. (Hamric et al., 2009), to assess readiness for change and address contextual barriers and facilitators. Once the prospect of change is a reality, Rogers and Shoemaker's Theory of Change can provide an understanding of how to initially communicate the goal of change (Hibberd & Smith, 2006). To effectuate the actual change process the CNS can apply Kanter's Innovational Theory of Change to guide the promotion of "innovation and entrepreneurship" (Hibberd & Smith, 2006, p.556). A detailed discussion of each of these leadership theories is beyond the scope of this paper, however it is of note that developing the ability to successfully integrate theories related to group dynamics, roles and organizations is one of the Canadian Nurses Association (CNA) competencies expected of an APN (CNA, 2008).

According to Hibberd and Smith (2006) transformational leaders motivate others to take action by promoting equality and demonstrating ethical leadership. Drawing upon virtue ethics, the authors contended that a leader possessing virtues such as trustworthiness, fortitude, integrity and compassion, gain more respect from those they lead (p.401). An awareness of ethical theories can assist the CNS in recognizing ethical situations and knowing how to take actions. Therefore, a general understanding of a variety of ethical theories and ethical decision-making models is essential to be able to provide ethical leadership.

### **The Role of Research in CNS Practice**

The CNS can promote the importance of research-based practice among nursing staff, particularly in the example of developing a TCC program. Employing evidence-based practice (EBP) improves the quality of client care. The CNS can initiate quality improvement activities, assist in developing and maintaining unit policies and procedures, and work collaboratively to

improve service delivery. The CNS can bridge the research-practice gap by educating nurses how to find best current evidence to answer questions that arise out of clinical practice, appraise the evidence for validity, and apply the evidence in practice (Hamric et al., 2009).

Hamric et al. (2009) differentiated between the fundamental research competencies expected from the APN upon graduation and integration into the workforce, and the expanded level that is developed with experience and further education. The research competency at the fundamental level focuses on evaluating the use of research in individual practice and role modeling EBP for colleagues. At the expanded level, the focus is at a broader systems level, such as evaluating the use of EBP within a particular program and collaborating with the organizational leaders to incorporate EBP at the program or unit level.

The APN is well situated to collaborate in research, either through direct participation or idea generation, and can facilitate the application of research findings into practice (Hamric et al., 2009). Participating in research allows the CNS to demonstrate the impact of nursing care on client outcomes, and provides data regarding the cost-effectiveness of the program (Hibberd & Smith, 2006). Positive outcomes demonstrating care efficiency provides supportive evidence to justify the role to stakeholders, staff, and organizations. Research participation at the fundamental level includes collaborating with a researcher as an expert consultant on a project. At the expanded level, the CNS would be expected to take on the function of investigator or research partner. The CNS is in a privileged position for clinical inquiry as they have direct access to clients and can anticipate challenges to providing quality care.

**The APN as Transitional Care Coordinator**

Contrary to the physician-driven Chronic Care Model, the Transitional Care Model uses Master's prepared APNs in the role of transitional care nurse, the rationale being that the masters preparation reduces the variability in preparation of generalist nurses. In addition, Naylor and colleagues believe APNs need less supervision as a result of their leadership capabilities. APNs coordinate the discharge planning, act as the liaison for the interdisciplinary team, refer patients to community resources and services, coordinate or provide patient and caregiver education, and ensure medical follow-up is in place once transitional care is discontinued. Matching APN skills and expertise to the patient population's primary issues contributed to improved patient outcomes in testing of the model (Brooten et al., 2002).

According the the TCM website (2008), the skills required by the APN working in transitional care include: expert clinical skills and ability to practice evidence-based care; experience in both hospital and home care nursing; ability to operate autonomously and flexibly with maturity and confidence; and understanding of the health care system and the ability to navigate the system or access resources; an awareness of community resources and social services; the ability to form connections with community providers in order to decrease duplication in services; leadership competencies and the ability to negotiate change; effective communication skills; and the capacity to collaborate and form alliances with other care providers. Brooten et al. (2002) argued that clinical expertise lends credibility and creates trust in the ability of the APN to lead a transitional care team. It is especially important when implementing a new program and forming a new team that the APN demonstrate the variety of competencies and strengths they can bring to the position and make visible the contribution the

APN can have to the nursing profession.

The team at Penn State University involved with disseminating the TCM has developed a series of web-based training modules that prepare nurses to become transitional care nurses. Training includes access to a multidisciplinary team of experts to assist in addressing complex issues. In addition, the Penn research team offers access to and training for their clinical information system of evidence-based assessment tools and intervention protocols (TCM, 2008). The system can also be used to track the patient's clinical history.

Betz and Redcay (2005) discussed the dimensions of a Transition Service Coordinator (TSC) role in relation to APN competencies. The authors described the central focus of the role as that of clinical expert which involved developing standards of care and best practice principles, formulating individualized care plans, creating a referral network and referral procedures, constructing standard transition-related documentation records, and generating instructional and educational materials. As a consultant, the TSC can assist clients in determining eligibility for insurance programs and community support, consult with the interdisciplinary health care team, including linking patients with community physicians or pediatricians for chronic care management, and assisting with accommodation needs for schools. As a change agent, the TSC is an innovator, creating frameworks for care specific to practice context, advocating for training programs for staff, develops parent/family support programs, and is involved in policy making to effect systems change. As an educator, the TSC brings theory into practice, informing colleagues on transition theory, family systems nursing, intervention strategies, discharge resources, develops educational materials for colleagues and for client/family use, and raises awareness of health literacy issues. As a researcher the TSC ensures

principles of transition care are evidence-based, they design and implement transition-related research projects, and support colleagues in applying evidence to care, generate or support colleagues in generating research proposals, and are involved in program evaluation and quality improvement initiatives.

The complexity of the CNS role requires integration and expert deployment of the APN competencies. The role of the TCC is equally comprehensive and requires a combination of clinical expertise and leadership skill, along with the ability to effectively integrate theory into practice. Having discussed the various theoretical underpinnings for transitional care, I will now provide a case example in order to synthesize the theoretical and conceptual knowledge explored and apply it in the practice context.

**Part IV: Case Example**

This paper has provided a discussion on the elements of transitional care coordination based on the Chronic Care Model and Transitional Care Models. The theoretical underpinnings of transitional care have also been explored. Appendix B provides a summary of the dimensions of the TCC role based on the elements discussed in this review of the literature. A case example is an effective way to demonstrate the complexity of planning involved in the transition of a child with complex care needs between hospital and home. Working through the case example will allow for a visualization of how the Transitional Care Coordinator role could be enacted.

***Riley is a one month old who was diagnosed antenatally with a complex congenital heart defect of hypoplastic left heart and coarctation of the aorta. After birth, Riley remained in hospital for stabilization and surgery for a BT shunt, the first step in a staged procedure to correct his heart defect. New immigrants to Canada, neither parent was employed and they lived in low-income housing. They roomed-in with Riley during his stay at the hospital.***

Case management: Referral for this family should be made to the transitional care coordinator well in advance of the anticipated discharge date. An individualized plan of care should be devised and the discharge criteria should be clearly articulated with the family participating to the best of their ability in setting discharge goals. Theory-based practice: The TCC must provide family-centred care, recognizing that the parents will require caregiver support. Attention should be paid to facilitating attachment between Riley and his parents and counselling these first-time parents in adapting to their new role as parent care-givers. The TCC should support the family through their feelings of loss of their dreams of having a healthy “normal” baby and assist with cognitive reframing to adapt to their new reality. The TCC can utilize the Calgary Family Assessment Model to determine internal and external influences on

health and illness, family support networks, and family strengths and competencies. This family will have the need to access many resources in order to assist with finances and navigating a system in an unfamiliar country. A referral should be made to Social Work in order to assist with accessing resources. As new immigrants, and new parents to a child with a heart defect, this family is experiencing multiple simultaneous transitions, and likely multiple stressors. The TCC can assist the family in clarifying expectations and setting goals for the future. The TCC can assess if any friends or family are accessible to participate in caregiving and provide respite to the parents. Arrangements may be necessary to educate these individuals about Riley's care needs.

***The family has complex communication needs due to limited English comprehension. Interpreter services for their primary language are lacking, requiring a modified approach.***

Education and counselling: Family education should begin from day 1 in a staged approach utilizing teach-back methods and concluding with a care by parent trial prior to discharge. Interpreters should be used at every opportunity. Education should focus on the diagnosis of complex CHD, anticipated care demands, and surgical and medical interventions. The TCC can address the lack of English literacy through a modified approach to communication and coordinate teaching efforts with the staff nurses. Colour-coded medication systems or visual instructions for scheduling are creative examples of ways the TCC can meet the family's literacy needs. Exploring the theory-based concepts of meaning and expectations will be a challenge.

***Members of the interdisciplinary team involved include social worker, community liaison nurse, dietician, occupational therapist, physical therapist, clinical pharmacist, pediatric cardiologist, pediatric electrophysiologist, pediatric cardiac surgeon, nursing support***

***service coordinator from community health, coordinator for home care nursing services, Ministry of Children and Families, and interpreters. Additional resources to be accessed through social work include a doula, personal support worker, housekeeper, and life skills coach.***

Case management: The TCC acts as the liaison between members of the interdisciplinary team. The TCC facilitates team and family meetings as necessary and keeps communication current and accurate between all members of the team. The TCC must anticipate the need for medical interpreting services for future physician and specialist visits and can arrange access to this through the Provincial Health Services Authority. Riley will need a referral to a pediatrician and the TCC can ensure the pediatrician receives a summary of Riley's medical history and plan for follow up with the cardiologist and cardiac surgeon. Since Riley has not left the hospital since birth, he will need to have newborn and audiology screening arranged. Due to the nature of his condition and the risk for impaired cognitive function, Riley will also need a referral to the Infant Development Program. The TCC will need to communicate with the Nursing Support Services Coordinator to provide a summary of Riley's condition and care needs in order to determine eligibility for programs offering nursing respite and funding for medical equipment and supplies.

***Riley was unable to successfully transition to oral feeds. He is on intermittent nasogastric tube feeds and uses formula that requires special preparation. His mother pumps her breast milk but has a limited supply. When breast milk is available, she supplements the milk by adding powdered formula in order to provide the calorie content recommended by the cardiac dietician.***

Education and counselling: The parents will need instruction on all aspects of NG tube feeding including placement checks, administration of bolus feeds, pump operation, cleaning and replacement of equipment, and a contingency plan for tube reinsertion in the event it is dislodged. Riley's parents will need instruction in formula preparation and support for breastfeeding and pumping. Case management: consultation with a lactation consultant may be necessary. The TCC will need to coordinate a feeding pump rental and order the required equipment and supplies. The parents will need to be provided a list of supplies to order on a monthly basis and instructions on where supplies can be ordered from. The family should also be referred to the Home Enteric Nutrition Program.

***Riley's condition is further complicated by an intermittent cardiac arrhythmia, atrial tachycardia. He is shunt-dependent and needs intermittent oxygen saturation monitoring. He will need close monitoring of his weight in order to ensure that the nutrition plan is effective.***

Education and counselling: Riley's parents will need to be instructed on how to assess for signs and symptoms of atrial tachycardia and who to call if this occurs at home. Case management: The TCC will need to arrange for a home monitor for ongoing assessment of Riley's cardiac rhythm. The family will also require a home oxygen saturation monitor, instruction in its use, and emergency management teaching in the event that Riley desaturates. The TCC will need to provide the parents with a scale for home monitoring of Riley's weight and devise a plan to have the parents communicate the data with the health care team for prompt identification of problems. The local ambulance department should be made aware of the special circumstances for this family through a plan of care. CPR training for the parents and family caregivers should be arranged at the first available opportunity.

Surveillance: Throughout the interactions with the patient and the family, the TCC should be observing and monitoring for physical signs of readiness for discharge in the patient, and knowledge gaps or inconsistencies in the care provided by parents. Prior to discharge, the TCC should conduct a home visit with the family to assess the home environment for safety hazards and assist the family in setting up the environment for the patient's care needs. During the post-discharge home visits, the TCC should assess the family's comfort level with procedural care. The opportunity to monitor for signs and symptoms of declining health in the home can allow for prompt identification of issues, improving outcomes. The TCC in the home can ensure there are no issues related to Riley's arrhythmia, oxygen saturation levels and weight and further assess the parents for any knowledge gaps not recognized with in-hospital surveillance. It will be essential for this family to have access to a TCC through phone, or preferably web-conferencing so that non-verbal communication can contribute to a better understanding for parents. Riley's condition will be chronic, with surgery a palliative measure, and he will need consistent follow-up once in the community.

Within the current system, Riley remained in hospital for two months, not because his medical condition necessitated hospitalization, rather because his discharge preparation was complex. With a TCC model of care, this discharge could be expedited with a prioritization system. Once the family can demonstrate mastery of the basic care required to meet discharge criteria and provide safe, competent care in the home, the TCC nurse could provide more frequent home follow-up and continued education, case management, and care coordination after the patient returned home. This reduction in number of days the patient spent in hospital would result in substantial health care cost savings for the province.

**Part V: Discussion**

**Recommendations to Address Service Gaps**

The changing epidemiology of children living longer with multiple chronic health problems being cared for in the home environment necessitates attention to methods of reducing health care costs and improving care efficiency. Existing research provides a framework for the provision of transitional care among hospitalized elders. In order to determine the specific transitional care needs of children with complex and chronic medical conditions, a comprehensive needs assessment must be performed by an APN specializing in transitional care. Research exploring the subjective needs of parents, and the transition experience from the family perspective could provide relevant information for planning services.

The ultimate goal is to influence health care administrators and policy makers to embrace innovative models of care to address the changing needs of children with special health care needs. To achieve the goal of high-quality, affordable care for high-risk children, clinical systems must be redesigned. These systems must operate using a framework of care that values prevention of poor and costly outcomes and promotes continuity of care. Existing models and frameworks that have empirically demonstrated positive patient outcomes avoids the need to reinvent the wheel. In addition, these models offer comprehensive resources, tools, and educational preparation that can be adapted to suit the context for care.

Program development should be linked to policy reform; it is essential to advocate for policies at the government level to support children with complex and chronic medical conditions to receive appropriate care in a coordinated and consistent manner. Funding should be made available to support program development that will ultimately result in cost-savings to the system.

**Directions for Future research**

A literature review by Wise et al. (2007) discovered a paucity of empirical evidence on the impact of care coordination services for CSHCN. The authors concluded that the lack of literature makes it difficult to identify which strategies, if any, are most effective. In addition, lack of consensus on definitions for both CSHCN and care coordination makes it difficult to compare studies assessing program characteristics and effects, or create program measures specific to CSHCN. In order to accurately measure outcomes, more focused metrics and performance measures to evaluate program effectiveness for are needed. Wise et al. (2007) state there is a need to evaluate the impact of care coordination strategies for children on health outcomes, quality of life, and cost benefits using rigorous study design.

Given that transitions occur over time, Kralik et al. (2006) expressed the need for longitudinal research exploring experiences through different phases in transitions; methodologies extending beyond a single event need to be considered. Other areas for exploration include whether culture or gender affect the experience of transition. It would be useful to determine if there are critical points for experiencing transition where intervention could have the greatest impact. Identifying the roles of parents in facilitating their child's transitions could also prove useful. Betz and Redcay (2005) believe empirical testing is needed to measure pre- and post-outcomes for transition planning for families, beginning with assessment to long-term follow up. Finally, there is a need to develop and test standardized tools to be used in transitional care assessment and intervention.

**Conclusion**

Children with multiple chronic or complex conditions receive care from a plethora of providers and this care is often disjointed. Fragmentation in care has been linked to adverse events, low satisfaction with care and high levels of hospital re-admission (Naylor & Keating, 2008, p.65). According to Naylor and Keating (2008), factors which contribute to gaps in care during transition include poor communication, inadequate education of caregivers, limited access to essential services, absence of a single person to ensure continuity of care, and language and health literacy issues.

The transition from hospital to home can be anxiety provoking. During hospitalization, parents are required to assimilate an incredible volume of information about their child's condition, treatment and long term management. Despite how prepared parents may feel upon discharge home, it would be difficult for anyone to anticipate the various situations that may present themselves once home. Therefore, follow-up and a reliable resource person for parents to contact are essential to ensure that parents have the support they need as new questions and concerns arise.

The CCM provides an established program of education and resources to assist and support clinical practice redesign and quality improvement initiatives at the systems level. The TCM provides a framework for care delivery within the system which guides the actions and interventions of the APN leading the transitional care team. Utilizing relevant elements of each of these two models can result in care that is coordinated within and between systems while anticipating and addressing patient needs related to their chronic condition beyond the acute care setting.

Transitional care coordination, as presented in this paper, has the potential to reduce length of hospital admission, decrease overall cost of care, improve patient outcomes, decrease duplication of services, and increase system efficiency. The APN possesses the appropriate mix of skill, expertise, theoretical knowledge and leadership ability to effectively engage in the delivery of transitional care coordination services. In addition, the APN is well suited to advocate for role creation to meet patient needs at the systems level.

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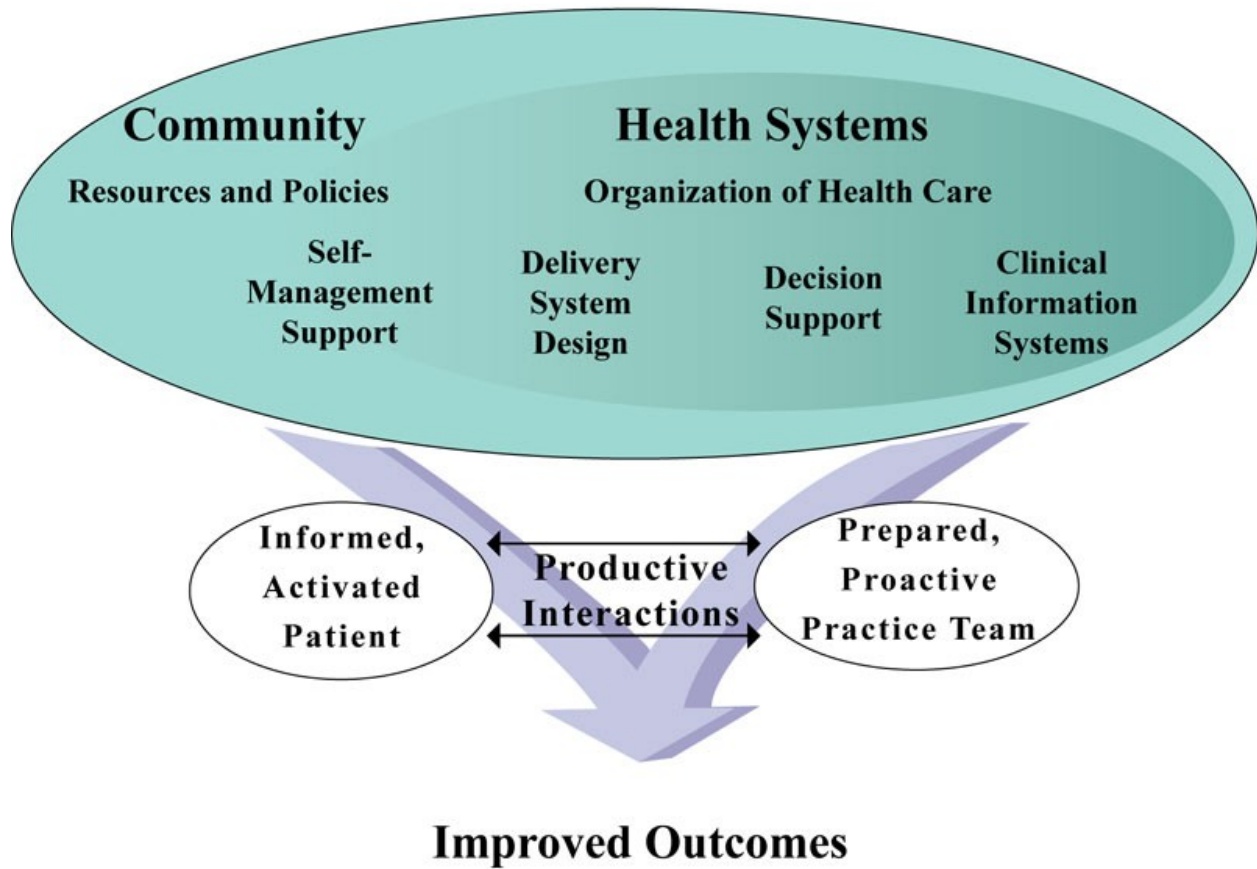
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Appendix A

Chronic Care Model Diagram

### The Chronic Care Model



Developed by The MacColl Institute  
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Source: Wagner E. H. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*, 1, 2-4

Appendix B

Transitional Care Coordinator Interventions

Theory-based Nursing TCC Interventions	
<b>Family-centred Care</b>	<ul style="list-style-type: none"> <li>• Acknowledge the family as context</li> <li>• Form collaborative partnerships</li> <li>• Engage in mutual goal setting</li> <li>• Recognize the family as expert on their child</li> <li>• Provide caregiver support</li> </ul>
<b>Family Systems Nursing</b>	<ul style="list-style-type: none"> <li>• Consider family as client</li> <li>• Embrace a holistic perspective</li> <li>• Recognize that the family is a system in constant interaction with their environment</li> <li>• Identify internal and external influences on health and illness</li> <li>• Assist the family in identifying adaptive or maladaptive functioning patterns</li> <li>• Identify and draw upon family strengths and competencies</li> <li>• Utilize the CFAM for assessments</li> <li>• Utilize the CFIM for interventions</li> </ul>
<b>Transition Theory</b>	<ul style="list-style-type: none"> <li>• Acknowledge and facilitate incorporating role changes</li> <li>• Assess for simultaneous transitions: health/illness;</li> </ul>

	<p>developmental; or situational</p> <ul style="list-style-type: none"> <li>• Identify transitions experienced by individual family members</li> <li>• Help the family identify meanings associated with transitions</li> <li>• Clarify expectations</li> <li>• Facilitate goal setting</li> <li>• Access available resources</li> <li>• Assess social support available</li> </ul>
<p><b>Adaptation, Uncertainty, Meaning, and Coping</b></p>	<ul style="list-style-type: none"> <li>• Awareness precedes engagement</li> <li>• Assist family in identifying areas where change is required</li> <li>• Facilitate recognition of feelings of loss</li> <li>• Reality is constructed by the family</li> <li>• Identify collective stressors and their associated meaning for the family</li> <li>• Facilitate cognitive reframing</li> <li>• Aid in recognizing new meanings attributed to events</li> <li>• Identify knowledge gaps and clarify any misconceptions</li> <li>• Clarify expectations</li> <li>• Engage in collaborative goal setting</li> </ul>

	<ul style="list-style-type: none"> <li>• Provide education that is appropriate to the family's literacy level</li> <li>• Ensure information from all members of the health care team is consistent</li> <li>• Provide support and guidance</li> <li>• Identify what coping strategies have worked for the family in the past</li> <li>• Access required resources</li> <li>• Assess social support available</li> </ul>
<p><b>TCC Activities in the Hospital Setting</b></p>	
<p><b>Case Management</b></p>	<ul style="list-style-type: none"> <li>• Initiate patient contact within 48 hours of hospital admission</li> <li>• Develop individualized care plans</li> <li>• Access laboratory findings</li> <li>• Coordinate nursing care</li> <li>• Coordinate discharge planning</li> <li>• Assess finances and need for social work support</li> <li>• Act as liaison for the interdisciplinary team</li> <li>• Plan and facilitate family and team meetings</li> <li>• Order supplies and secure rental of medical equipment</li> <li>• Refer patients to community resources and services</li> <li>• Ensure medical follow-up is in place</li> </ul>

<p><b>Education and Counseling</b></p>	<ul style="list-style-type: none"> <li>• Start teaching early and allow for repetition and care by parent observation</li> <li>• Engage in goal setting, planning, and assist with problem-solving</li> <li>• Coordinate or provide caregiver education related to illness, treatment, and health prevention and promotion</li> <li>• Generate instructional and educational materials</li> <li>• Devise resources for communicating with patients with limited English literacy</li> <li>• Educate health care team on issue of low health literacy</li> <li>• Educate staff on transition theory and issues related to transitional care</li> </ul>
<p><b>Surveillance</b></p>	<ul style="list-style-type: none"> <li>• Monitor for physical and psychological signs and symptoms</li> <li>• Observe medication set-up and administration</li> <li>• Assess mobility and ability to transfer safely</li> <li>• Appraise the home environment for suitability for care and equipment set-up</li> <li>• Observe nutrition related factors</li> <li>• Communicate observations with the team</li> </ul>
<p><b>Clinical Expert</b></p>	<ul style="list-style-type: none"> <li>• Develop standards of care and best-practice principles</li> </ul>

	<ul style="list-style-type: none"> <li>• Develop standardized documentation records</li> <li>• Create referral procedures</li> <li>• Create a referral network with community providers</li> </ul>
<b>Consultant</b>	<ul style="list-style-type: none"> <li>• Provide patient history to community health coordinator to determine eligibility for support programs</li> <li>• Assist community health with referral for special accommodations in schools</li> </ul>
<b>Change Agent</b>	<ul style="list-style-type: none"> <li>• Create a framework for care that is context specific</li> <li>• Advocate for continued staff training</li> <li>• Develop parent/family support programs</li> <li>• Be involved in policy creation</li> </ul>
<b>Researcher</b>	<ul style="list-style-type: none"> <li>• Integrate evidence-based practice and disseminate new nursing knowledge</li> <li>• Design and implement transition related research</li> <li>• Become involved in program evaluation and internal monitoring</li> <li>• Initiate quality improvement efforts</li> </ul>
<b>TCC Activities in the Home Setting</b>	
	<ul style="list-style-type: none"> <li>• Provide home follow-up within 48 hours</li> <li>• Provide TCC accessibility by phone</li> <li>• Assess for issues with medication administration and preparation</li> </ul>

	<ul style="list-style-type: none"><li>• Monitor symptoms and review management</li><li>• Assess diet, activity, sleep, and psycho-social support</li><li>• Continue to coordinate medical follow-up as needed</li></ul>
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