

School of Nursing and Midwifery

**Mothers' Knowledge and Understanding of their Child's Care at
the Time of Cardiac Surgery**

Mary Tallon

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Master of Science (Nursing)
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DECLARATION

“To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material that has been accepted for the award of any other degree of diploma in any other University”

Mary Tallon

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ABSTRACT

The parents of young children who require cardiac surgery are often distraught because they fear their child may die or have long term health and developmental problems. Furthermore, parenting a seriously ill child often involves a great deal of uncertainty, due to a lack of knowledge and understanding about the child's condition and subsequent care. Parents frequently report a sense of powerlessness which can be overwhelming. In this situation it is particularly difficult for them to process the medical and nursing information they are confronted with. There is some evidence to suggest that the experience of distress affects attention and memory. This is significant because children's neurocognitive development may be affected by the condition and subsequent surgery and appropriate parental care is especially important at this time.

This quantitative cross sectional study aimed to validate an instrument which was developed to measure maternal knowledge and understanding (MKU) at the time of heart surgery and to also explore the impact that stress, anxiety, depression, and social support may have on MKU. Mothers attending the Children's Cardiac Centre at Princess Margaret Hospital for Children between Aug 2008 and April 2010 were recruited to participate. Validated instruments were used to measure levels of maternal stress, anxiety, depression and social support, while a consensual instrument was developed to measure MKU. Data were collected using a questionnaire. Descriptive, bivariate and multiple regression analysis were undertaken.

Ninety one out of 146 mothers approached (61.4%) consented to participate in the study. The MKU scale (MKUS) demonstrated reasonable internal consistency (Cronbach's Alpha .78). Twenty-nine per cent of mothers were experiencing significant stress, 28% anxiety and 22% depression at the time of questionnaire completion. Statistically significant relationships were found between the complexity of the child's operation and maternal depression with mothers of children who were undergoing more complex procedures reporting higher levels of depression ($p = 0.048$). Financial strain was found to be associated with higher levels of maternal anxiety ($p = 0.027$). Analysis of variance confirmed a relationship between increased maternal anxiety and lower MKUS (p value= 0.036). While not directly associated with MKUS, maternal stress and depression were identified as mediators to MKUS through depression and anxiety. A significant relationship was found between mothers who did not see relatives at all, or often enough and lower MKUS (p value .005). Also mothers who reported they did not have someone to talk to outside the home recorded lower MKUS (p value .005). A multiple regression model identified increased maternal anxiety, not seeing relatives often enough and no outside talks as independent predictors for lower MKU.

This study examines the effects of maternal demographic factors, stress, anxiety and depression, and, social support on a mother's understanding and capacity to relate this information to the care of her child at the time of cardiac surgery. The findings in this study call for more research to further develop the MKUS for potential adaptation across wider range of settings where care is provided for the seriously ill children in hospital. Examination of this research question also highlights the importance of the care of the child in the context of family and community. These findings challenge paediatric nurses to further contemplate the frameworks that support the family-centred care framework. This research invites paediatric nurses, in addition to maternal attachment, to bring more formally consideration for the influences of bioecological embedding and the family's physical, psychological and social capital to acute paediatric nursing practice. Formal consideration for these factors within nurse-family relationship building and communication could potentially bring more timely attention to factors that influence a mother's understanding of her child's condition and care in the acute paediatric hospital setting.

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LIST OF ABBREVIATIONS

CPB	Cardiopulmonary bypass
DASS	Depression, Anxiety and Stress score
FCC	Family-Centred Care
MKU	Maternal Knowledge and Understanding
MKUS	Maternal Knowledge and Understanding Scale
MSSSI	Maternal Social Support Index
RACHS	Risk Assessment for Congenital Heart Surgery
PedsQL	Paediatric Quality of Life Inventory
PICU	Paediatric Intensive Care Unit
PMH	Princess Margaret Hospital
SEIFA	Socioeconomic Index for Areas

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INTRODUCTION

When an infant or young child is diagnosed with congenital heart disease and is in need of surgery, the whole family is typically thrown in chaos (Brosig, Mussatto, Kuhn, & Tweddell, 2007). For parents, the understanding that their child has a serious life-threatening condition and is in urgent need of surgery, which may lead to complications including death, is a major source of stress and anxiety. For some the experience can be overwhelming. At this time the affected children require optimal care from their parents at a time when they may feel least able to provide it (Colville, et al., 2009).

The earliest years of a child's life are the most crucial for life-long development because physiological processes, such as gene expression, neural sculpting, and the development of stress responsiveness are at their height of activity (Maras & Baram, 2012). When a very young child experiences congenital heart disease and corrective surgery, the risk to overall development is as great a concern as the outcome of the surgery itself. The child's principal care-giver, usually the child's mother, plays the most significant role in helping the child regulate these physiological processes through attachment. Research findings consistently show that infants and children who receive the appropriate emotional and physical care and stimulation from their mothers achieve healthier physical, emotional and developmental outcomes than those who do not (Atkinson, et al., 2000).

The capacity for parents to cope in this situation is dependent on a range of personal, social, and cultural characteristics. For example, some mothers are very confident in their ability to parent (Liu et al., 2012). This confidence might come from their education or experience in caring for young children (Dewalt & Hink, 2009). Some mothers are very well supported within the home and by a wide circle of family and friends (Rini et al., 2008). And some mothers, who are within the dominant cultural group, may always experience acceptance and tolerance. On the other hand many mothers are neither confident, well supported, nor culturally accepted (Benzies et al. 2011).

A mother's general health and wellbeing is also very important for the care of her child. When a mother experiences physical or mental health problems it may affect her ability to relate to her child and to understand important information about providing appropriate care (Beardslee, Gladstone, Wright, & Cooper, 2003). Even

when a mother is healthy, confident, and well supported at home and by family and friends, the child's diagnosis and requirement for surgery can significantly affect her ability to think clearly (Axia, 2004). In order to be able to offer the best support to families in this situation, nurses must know how to assess the family's psychosocial circumstances and then plan, implement and evaluate appropriate nursing care.

Aims

The aims of the research are two-fold. Firstly, to develop an instrument that may potentially serve as an indicator for nursing intervention by effectively measuring mothers' knowledge and understanding of their child's heart surgery and care.

Secondly, to examine the effect of stress, anxiety, depression, and social support on the participating mothers' knowledge and understanding of their children's heart disease and capacity to provide appropriate care at the time of their child's heart surgery.

Research questions

The following research questions were explored:

1. Is it possible to measure a mother's knowledge and understanding of her child's cardiac surgery and subsequent care using an instrument specifically developed for this purpose?
2. Are heightened levels of stress and anxiety and lower levels of social support associated with lower levels of maternal knowledge and understanding at the time of surgery?

Thesis outline

Chapter Two consists of a review of the literature which is presented in three sub-sections. In the first sub-section the reader is introduced to the bioecological theory of early child development that is frequently applied in contemporary research and practice. Here, the significant influence of the family on children's health and development is highlighted. Next, the family and community resources conceptual framework is introduced to help identify the wide range of family characteristics, such as financial circumstances, parental mental health, and social support. These have been found to predict child health and developmental outcomes (Kendall, 2003). In the second sub-section the nursing literature that specifically examines parents' experience of having a child with congenital heart disease is critically

examined. The strengths, limitations, and gaps in the research are identified. This section of the review highlights the lack of attention given to the impact of stress on the family, child development, and empowerment theory in the acute paediatric setting. In the third sub-section the research literature regarding the effects of stress on cognition is first synthesized and the findings are then applied to the understanding of how parents whose children are about to undergo surgery for congenital heart disease might fail to retain complex medical and nursing information. Here, evidence supporting the importance of relationship building and therapeutic communication in the nursing care of children and their families is examined.

Chapter Three outlines and describes the methodology. The study design is introduced and the steps taken to ensure rigour are explained. How mothers were informed about the study and invited to participate is described. Also outlined is the method of data collection in the form of a questionnaire including validated measurements for depression, anxiety, stress and social support and inclusive of a set of consensual questions to evaluate mothers' responses about their child's heart disease and care. The methods of data analysis are introduced and explained, including the assessment of the internal consistency of the consensual tool used to measure mother's knowledge and understanding. Finally, the processes of managing ethical issues and the safe storage of information by the researcher are described.

In Chapter Four the results are presented and explained. Participation rates and the characteristics and features of participating mothers are described. Descriptive analysis of maternal and child demographic data is presented, as are the results of internal consistency analysis with regard to the development of the consensual maternal knowledge and understanding instrument. One-way analysis of variance, between maternal depression, anxiety and stress and MKUS as both independent and dependent variables are presented. The section concludes with the results of linear multiple regression analysis to estimate the proportion of variance in MKUS that can be accounted for by a number of variables in combination.

In Chapter Five the major findings of the study are summarised, interpreted, and discussed with reference to the extant literature. The importance of family stress, anxiety, depression, and social support for MKU and the care of a child who requires heart surgery are deliberated and the reasons for including these factors in clinical

nursing assessment discussed. The integration of a nursing measure for maternal knowledge and understanding into nursing assessment in the acute paediatric setting is contemplated. Implications for nursing practice in the paediatric hospital setting are discussed. Following this, the strengths and limitations of the study are identified and discussed in some detail. Finally, future recommendations for nursing research are made as a result of the findings from this study and conclusions drawn within this thesis.

2 REVIEW OF THE LITERATURE

Introduction

The parents of young children who require cardiac surgery often experience significant distress because they fear their child may die or have complications that seriously affect development. This concern is substantiated with research evidence indicating an increased risk of neurodevelopmental problems for children following heart surgery early in life (Wernovsky, 2003). In practice, many parents are anxious and frightened. This makes it difficult for them to understand new, and often complex, medical and nursing information. And yet, it is critical that they do understand this information and have the capacity to provide appropriate care for their child who has undergone surgery. Children spend a relatively short period of time in hospital and it is the parents who will have the most influence on their child's long term health and development (Li, 2005). No matter how capable the parents, they usually require a great deal of support at this time.

In order to make the purpose of this research clear to the reader, the following review of the literature will introduce a number of theories, concepts, and evidence-based knowledge relevant to the topic. Firstly, bioecological theory will be introduced as it places the developing child in the context of the family and the community, as well as the broader social, cultural, economic, and political milieu. The family and community resource framework will also be introduced to focus attention more specifically on the mother's level of psychological functioning, and psychosocial processes and social supports within the family and community. This conceptual framework is central to the current research as the concepts have been operationalized in the questionnaire that was administered to mothers at the time of their child was undergoing cardiac surgery. It is used widely to guide assessment by a range of health and social professionals, including community child health nurses (Zubrick, Williams, Silburn & Vimpani, 2000). The application of this framework may potentially help paediatric nurses to identify areas of strength and / or need within the family providing opportunities for earlier intervention.

Secondly, as this research focuses on mothers whose children have undergone cardiac surgery, the incidence, diagnosis, symptoms, and treatment of congenital heart disease are outlined. The evidence for the impact of congenital heart disease on

a child's neurodevelopmental outcomes is critically examined along with evidence for the effect of children's serious illness on the family.

Thirdly, it is important for the reader to know about the cognitive process of developing knowledge and understanding. Literature examining the effects of stress, anxiety, and depressed mood on information processing is related to the experience of families caring for their seriously ill child. The importance of effective nursing intervention is highlighted.

Typical child development

Introduction

Human development is shaped by the constant interaction between biology and experience. Healthy caring relationships serve as the building blocks for healthy development (Shonkoff & Phillips, 2000). Babies are born ready to interact with their environment. Physical, emotional, and cognitive development depends on how children respond to their physical and psychosocial environment, and especially to those caring for them (Kendall, Van Eekelen & Mattes, 2009).

Contexts of development

It is widely accepted that a systems theory perspective is the most useful way to organise knowledge and understanding of child development (Kendall, Van Eekelen, Li & Mattes, 2009). The systems theory perspective is derived from theory and research in a wide variety of academic disciplines ranging from neuroscience to sociology. Bronfenbrenner's bioecological model of early child development is a systems theory that has become popular with researchers as well as practitioners (Kendall & Li, 2005). It provides a foundation on which to study the multiple contexts within which human development is embedded. Influences are identified in layers beginning with those close to the child with the parents, family and early care making up the 'microsystem'. This is the earliest influential level where the biological development of the child and the stimulation, nurturance, and care-giving activities of the parent(s) interact. The care-giving actions and interactions of the parents are critical to the child's health and development. Research evidence indicates that children who have their needs met are more likely to achieve healthy physical, mental and cognitive development (Luthar & Brown, 2007). Meeting a child's health and developmental needs requires some maternal understanding of the child's needs, age and developmental stage, and health status. When a child is

seriously ill, this is especially important as the care provided by the mother is crucial. When regular mutual interaction and care is unavailable or insufficient, the processes of emotional, attentional, and social regulation can be significantly disrupted with negative consequences for the child's long-term physical and mental health, and cognitive development (Taylor, Way & Seeman, 2011).

Influences outside the home, such as child care, school, and the neighbourhood settings, also impact on developmental outcomes. Bronfenbrenner referred to these settings as the 'mesosystem'. In addition to the mesosystem, contexts with which the child does not participate, such as parents' place of work, the local council, and the provision of community services, also have an impact on the child's developmental outcomes. These contexts are referred to as the 'exosystem'. While relevant to all children, these contexts are especially important when considering the needs of the seriously ill child. In recent years, the length of time children spend in hospital has been considerably reduced (Darbyshire, 1995). At the same time, many women return to work, at least part-time, soon after the birth of their child (Maggi et al, 2011) Family access to information, facilities and services such as early education, quality child care, health care, and social supports are very important. Following discharge from hospital, access to local support and services is likely to influence how parents manage their child's ongoing recovery with implications for long term health outcomes.

Finally, social, cultural, economic, and political factors, such as employment opportunities and the health care system, that influence early child development, are referred to as the 'macrosystem' (Bronfenbrenner & Ceci, 1994). A great deal of evidence supports that fact that these broader structural factors have a substantial impact on child development as well as health and well-being across the life course. They are the social determinants of health and development (Hertzman, 2009; WHO, 2009). Structural factors, such as employment opportunities and discrimination, affect families and children, but they are largely beyond the control of the individuals themselves.

Bronfenbrenner's bioecological model distinguishes between influences on development from the intimate to the global. It is currently used by community nurses working with young children and families to assess, plan, implement, and evaluate appropriate nursing care. The remainder of this section will review

evidence-based literature that explains in greater detail how families influence the health and development of children, including those who are seriously ill.

The influence of the family

A great deal of biomedical research is now focused on better understanding the developmental origins of health and disease (Juster, McEwen & Lupien, 2010). Development in utero and early childhood is now known to be critical for life-long health and well-being (Danese & McEwen, 2011). It is at this time that epigenetic processes emerge, gene-expression takes place, the brain is formed, and neurones become “wired-up”. At this time the developing fetus and child is extremely sensitive to their own internal physiological environment as well as the external physical and psychosocial environments (Kendall et al, 2009). Through complex psycho-neuro-endocrine-immune and metabolic pathways that are now the subject of intensive research, the actions and behaviours of parents and other family members become biologically embedded (McEwen & Gianaros, 2010). The attachment of an infant or young child to their mother is one of the most important building block of development (Dickstein, Seifer, & Albus, 2009). Maternal attachment essentially shapes a child’s capacity to relate and respond to their environment. It is also associated with protective factors including parental warmth, coping and competency (Howard, Martin, Berlin & Brooks-Gunn, 2011). How a mother relates to her child provides the conditions for the infant’s regulation of emotional arousal and response, with implications for emotional development and relating to others throughout life (Raikes & Thompson, 2008). The attachment experience for the child therefore, carries significant implications for the child’s developmental processes of cognition, perception, emotion and motivation. The distress a mother may experience, associated with her infant’s diagnosis of a serious health problem and need for major surgery may disrupt the quality of attachment (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003).

More broadly, psychosocial factors within the family, such as maternal mental health, family relationships, the experience of life-stress, and social support can have a significant impact on the child’s health and development. Researchers and policy makers in Australia and internationally use the Family and Community Resource Framework to identify financial, physical, human, and social capital resources within families and communities that support children’s development (Kendall and Li,

2005; Zubrick et al., 2000). Within the broader bioecological model, the framework is a useful tool to guide the exploration of literature regarding maternal and family characteristics that give rise to compounding stress, and, the effects on both parents and their children.

As to financial capital, money problems are, perhaps, the biggest cause of stress for families, even in wealthy countries like Australia. While absolute poverty is associated with developing countries, research shows that relative poverty in developed countries makes significant contribution to poor health outcomes (Aber, Jones, & Raver, 2007). Financial strain is important because when a child is hospitalised with a serious illness, it may lead to arguments between parents. This, in turn can be associated with other life stresses, and potentially distract them from retaining important information related to their child's condition and care (McEwen & Gianaros, 2010). Research findings also support associations between financial strain and socioeconomic disadvantage, poverty, mental health problems and low self-esteem (McEwen & Gianaros, 2010). These factors, individually or collectively, are likely to further compound the experience of stress for affected parents and their capacity to manage (Beardslee & Knitzer; Evans, 2005; Slack et al., 2004; Votruba-Drzal, 2006).

Access to an appropriate vehicle is an example of the physical capital of the family. According to the Australian Bureau of Statistics (2001) households without a car are highly correlated with areas of greater socioeconomic disadvantage. When a child is in hospital, mothers without a means of transport may experience additional stress managing and responding to the needs of her other children at home (Burke, Harrison, Kauffmann, & Wong, 2001). Following discharge, the difficulties parents experience related to accessing important services and support are critical to their child's recovery and long term health (Axia, 2004). This is important because over recent years, the time children spend in hospital has reduced. Parents are often required to attend additional hospital or clinic follow up appointments following discharge to support compliance with their child's special care needs in the home (Howard & Brooks-Gunn, 2009).

Characteristics of parents including education, mental and physical health, and motivation are known as human capital. Each of these resources can be thought of as a resource or asset. Thus an individual with a university degree has more education

assets than an individual with a high school diploma. However, the university graduate with mental health issues may have less over-all human capital than the well-adjusted high school graduate. Research confirms that higher levels of parental human capital are associated with better child health and developmental outcomes (DeWalt & Hink, 2009). Children who are born to parents with higher levels of education and self-efficacy, for example, are likely to be more confident and have the desire to achieve at school and in life generally (Dawley, Loch, & Bindrich, 2007). Furthermore, human capital is associated with higher levels of health literacy which is the ability to understand and apply health information and is also an important determinant of health outcomes (DeWalt & Hink, 2009). When a child is seriously ill the parent's capacity to relate to medical and nursing information and use it in the care of their child is crucial.

The reality of having an infant or young child with a serious illness is likely to cause a parent to experience degrees of sadness and depression in some instances (Van Horn, DeMaso, Gonzalez-Heydrich, & Dahlmeier Erickson, 2001). A mother affected by a mental health problem may have difficulty relating to her child and be unable to provide the reassurance and care needed. This can increase the child's experience of stress and isolation in hospital (Preyde, 2007). A great deal of research shows that parental mental health problems, such as anxiety and depression, undermine positive parenting behaviours (Field, 2010). For example, in the presence of depression, parental goals may become less child-oriented where parents give less attention to their children, and are more likely to engage in coercive parenting practices (Dix & Meunier, 2009). Furthermore in the presence of maternal mental health problems, the additional stress of having a child with a serious illness requiring major treatment may serve as a catalyst for deterioration in mental functioning or promote a psychological crisis (Johnson, Hayes, Field, Schneiderman, & McCabe, 2000).

Trusting, reciprocal relationships between family members and others in the community can be a significant resource. These positive relationships, known as social capital, can be used to support parents and enhance children's developmental outcomes. For example, if two parents cooperate to share child care duties this has benefits for everyone in the family. The dyadic relationship between parents, family structure, working hours, and the interactive time spent with the child are all

important components of social capital that can support attachment, family functioning and adaptation to stress (Zubrick et al., 2000).

In addition to relationships within the nuclear family, relationships with extended family members, friends, and community members are also important for social capital. Research findings show that higher levels of extended family support are associated with an increased sense of maternal confidence and mastery, particularly in younger mothers (Surjadi, 2011). Also, improved maternal support, self-esteem, parenting skills and communication with their children are some of the benefits to mothers who meet in groups regularly outside the home (Lipman & Lipman, 2010). On the other hand, personal disadvantage such as financial strain, lack of established roots in the community and challenging child rearing responsibilities, have been linked to weaker support and reduced opportunities for engagement in reciprocal support (Harknett, 2011).

There is a significant literature in neuroscience and molecular biology that confirms the negative impact of family-life stress on children's health and development (Shonkoff, 2009). Examples of family life-stresses include: problems with money, unemployment, difficult relationships, the death of family members, and residential moves. Research shows that children who are exposed to prolonged, multiple family-life-stresses, during pregnancy and in early childhood have a higher incidence of physical health problems such as type II diabetes and hypertension in later life (Kendall, Van Eekelen, Li & Mattes, 2009). Further to this, more recent research calls for consideration for how parental resources such as psychological and social capital can influence biological embedding. (McEwen & Gianaros, 2010). This work supports the more recent notion that socio-economic factors, health and stress centre on the brain and suggests that parent resources, early learning, environmental exposures and nurturance can alter brain plasticity in children (McEwen & Gianaros, 2010). However, regardless of prevailing family-life-stress, when a child is seriously ill, most parents of sick infants experience considerable stress related to their infant's condition, the hospital environment and their confidence in their role as a parent (Majnemer et al., 2006).

Summary

This section has introduced the bioecological model and the family and community resource framework because it provides the theoretical basis for the data collected in

the current study. The role of the family in the care of the seriously ill child has been emphasised and factors that influence the capacity of parents to be able to care for their child appropriately have been identified.

Seriously ill children are especially vulnerable to poor neurodevelopmental outcomes and the parents of seriously ill children are at increased risk of failing to care for their child appropriately. These issues will be examined in the following section.

The impact of congenital heart disease on the child and the family

Introduction

Serious illness in early childhood has the potential to significantly disrupt the process of development which may have life-long consequences (Landolt et al., 2008). There is some evidence that congenital heart disease and subsequent surgery very early in life may negatively affect neurophysiological functioning (Shillingford, 2008). This section briefly outlines the incidence, symptoms, diagnosis, and treatment of congenital heart disease before examining the research literature regarding its impact on the child's neurodevelopment. The section finishes with an analysis of the impact of having a child with congenital heart disease on the family.

Incidence, symptoms, diagnosis, and treatment

Congenital heart disease continues to be the most common congenital abnormality in children in Australia and other Western countries. The incidence generally considered to be 8: 1000. The incidence varies globally depending on data recording, access to care, and mortality (Bernier, 2010). While most heart disease in children is congenital in nature, complications as a result of acquired heart disease such as Kawasaki Disease, rheumatic fever, and secondary cardiomyopathy adds to the overall prevalence. The diagnosis of heart disease often implies the need for diagnostic tests, surgery, and a lifetime of medical follow up (Marino, Bird, & Wernovsky, 2001).

Currently, in Western society, prenatal diagnosis is widely available. Studies have documented the benefits of fetal diagnosis to the newborn including planned delivery, prompt medical care and avoidance of severe cyanosis early in life (Daniels & Daniels, 2006; Jone, 2009; Mahle, 2001). For parents, the stress and uncertainty experienced in the prenatal period can be significant despite the expert help they receive from paediatric cardiology specialists and specialist nursing staff (Menahem,

2005). However, the early diagnosis of congenital heart disease is critical in reducing the pathophysiological effects of regulating appropriate circulation in the infant. The early prevention of hypoxia is crucial to reducing the impact of physical and developmental problems for the infant (Wernovsky, 2003). Treatment and surgery include admission to intensive care, the use of life support equipment, and, often the need for cardiopulmonary bypass, all of which pose additional risks to the child's health and development.

The impact on the child

A body of research evidence shows that infants' exposure to heart surgery for complex heart lesions is associated with increased risk of poor physical, cognitive, and neuromuscular developmental outcomes. Early studies have focused on survival rates and later on physical parameters, such as growth. Cohen (1999), for example, measured the physical growth of 65 children (Mean age 6.1 years; SD 1.4) following surgery for palliation of single ventricle anatomy. They were found to be significantly lighter in weight (z score -1.49) and shorter in height (z score -1.15) in comparison to their siblings and parents at the same age (Cohen, 1999). Later, with heart surgery becoming increasingly common, the greatest concern, other than growth, has been for the impact of cardiopulmonary bypass (CPB) on neurodevelopmental outcomes. Depending on the severity of the congenital heart disease, long-term follow-up studies have shown that up to half of the children affected will have a high incidence of mild or low intensity developmental problems related to speech, motor function, behaviour, or learning (Wernovsky, 2006).

As survival rates have improved significantly, recent studies have focused on the implications of delayed diagnosis and pre and post-operative events. For example, in a study by Tabbutt (2008) of 89 infants who underwent surgery for complex heart disease in early infancy, predictors for poor outcomes were identified. Cognitive and psychomotor developmental indices were used to measure the effects of perioperative, operative and genetic variables. Neurodevelopmental assessments were performed at one year of age. In multivariate analysis, predictors for poor outcomes were identified as: diagnosed or suspected genetic disorder (β 18.7, p .002); pre-operative intubation (β -9.1, p .02); and gestational age (β 2.4, p .011). These findings are important as they identify risks associated with the diagnosis of complex congenital heart disease that can further compound health and

developmental outcomes adding to the vulnerability of this group. The participating parents and infants in this study, who returned for evaluation, were largely of white race, born at term, and had a birth weight within normal centile parameters. It could be considered that neurodevelopmental outcomes could potentially further impacted in a sample of less advantaged infants. Interestingly, while not the focus of the study, the findings also highlighted associations between the incidence of death and poor follow up, lower socioeconomic advantage, and ethnicity in the infants who did not present for developmental evaluation.

The growing interest in neurodevelopmental outcomes has led to the examination of concentration and attention in children who have undergone cardiac surgery at an early age (Mahle, 2000; Quartermain, 2010; Wernovsky, 2006). In a study examining 109, 5 - 10 year old children post-surgery, Wernovsky (2006) found that 53 % were receiving remedial educational services and 15 % were assigned to a special classroom at school. Furthermore, these children were found to be three to four times more likely to have clinically significant inattention and hyperactivity than children in the general population. Having found these adverse developmental outcomes, the authors could not attribute them to any specific preoperative, perioperative, or postoperative events. These findings illustrate additional and often subtle neurodevelopmental vulnerabilities in children diagnosed with congenital heart disease and highlight the importance of developmental follow up and early recognition. While it could be said that further research is required to understand more about the association between congenital heart disease and poor developmental outcomes, especially in more socioeconomically disadvantaged children and families, the evidence to date for a relationship is very strong.

The impact on the family

The impact on the family of having a child with congenital heart disease can be significant (Mussatto, 2006). Disruption to family routine and reduced availability to enjoy leisure activities can have a negative effect on siblings and alter the family's lifestyle. Parents can experience significant interruption of their work schedule that can cause financial strain. This is particularly true if either parent is self-employed. Many families in Western Australia must travel long distances to access hospitals for appointments, tests and admission for surgery (Government of Western Australia Department of Health, 2012). These factors can be sources of considerable

psychological distress and strain which can upset family communication and contribute to conflict (Tong, Lowe, Sainsbury, & Craig, 2008). The need for a child to attend regular medical follow up, ongoing investigative monitoring, and often further surgery can be a source of constant worry for parents who are concerned about the possibility of further physical, emotional or developmental health problems. In an editorial comment, Mussato (2006) suggested that parental optimism present prior to their child's initial surgery was often replaced by a profound sadness as parents come to terms with the lifelong physical and psychosocial implications of their child's heart disease.

How parents and children perceive their circumstances remains critical to how they manage. With growing numbers of children with congenital heart disease surviving, there has been more research focusing on their quality of life. A study by Uzark (2008) examined the quality of life perspectives collected from 379 participating children and 475 parents who attended the cardiology outpatient department at the Children Hospital in Cincinnati in Texas. The quality of life perspectives were based on subjective experiences of the children and parents based on individual experience of their position in life in context with culture and value systems and in relation to their goals, expectations and concerns. The children ranged from pre-schoolers to adolescents and their perceived quality of life perspectives were compared with their parents using the Paediatric Quality of Life Inventory (PedsQL). Use of the PedsQL also provided access to a large normative database of ethnically diverse healthy children as well as children with chronic health problems that allowed evaluation of different specific populations. Measures for physical, emotional, social and academic characteristics were recorded demonstrating internal consistency of $\alpha > .7$ of the PedsQL measure. The findings showed significant differences recorded by the children affected by heart disease ($p = <.001$) and their healthy counterparts with in the 5-7, 8-12 and 13-18 year old age groups. Parental reporting, however, showed no significant difference between pre-schooler, young and older child groups and a p value of .05 in the 13-18 year old group. Interestingly, one in five children including those with milder disease reported impaired psychosocial functioning that did not appear to be recognised by parents in this study. These findings suggest disparities in parental perception and the potential for these to go unnoticed. These findings also support the importance for nurses to listen attentively to both parents and children.

Summary

This section outlined the incidence, symptoms, diagnosis, and treatment of congenital heart disease. The incidence of poor child neurodevelopmental outcomes was presented and the vulnerability of this group of children was highlighted. The effects of additional life-stresses on the family's communication and capacity to manage were briefly outlined. Differences between parent and child perceptions of quality of life were considered and the importance of listening intently to families supported.

The following section will review factors that impact the development of parental knowledge and understanding.

Factors that impact on a mother's knowledge and understanding about her seriously ill child's condition and care

Introduction

This section examines how stress and anxiety affect attention and memory and how a lack of parental resources, such as education and good mental health, can exacerbate the effects of life-stress. These factors are examined in relation to a mother's development of knowledge and understanding about her seriously ill child's condition and care in the hospital setting. The implications for the nurse's role in facilitating the development of parental knowledge and understanding are considered.

Attention and memory

Parenting a seriously ill child often involves a great deal of uncertainty due to a lack of understanding about the child's condition and subsequent care. In this situation it may be particularly difficult for parents to process the medical and nursing information they are commonly inundated with (Wong, 2004). Attention and memory are known to be the basic building blocks of cognition and they arguably lay the foundation for all cognitive processes (Ingram, Steidtmann, & Bistricky, 2008). When an individual experiences a strong emotional response such as distress, fear or anger, the limbic structures of the brain which are involved in regulating emotions, the amygdala, hippocampus, and pre-frontal cortex are stimulated and, in turn, the hypothalamic pituitary adrenal (HPA) axis leads to the secretion of cortisol, while the sympatho adrenal medullary (SAM) pathway leads to the secretion of catecholamines. Due to the direct effect through the limbic system and the indirect

effect through the HPA axis and SAM pathway emotional responses disrupt information processing and reduce the person's capacity to learn or understand new information (Taylor, 2007). In a study of mothers of children with congenital heart disease, Berant (2001) found, that mothers who were anxious were less likely to pay attention to what they were being told by medical and nursing staff. Berant reported that it was as if these mothers were avoiding the information to protect themselves emotionally. This is certainly the experience of the researcher who has worked for many years with the mothers of seriously ill children. It is also the experience of colleagues who care for these children and families. A comprehensive search of the literature in CINAHL and PsycINFO databases failed to uncover other published articles on this topic.

As discussed in a previous section of this review, the mothers of seriously ill children have different levels of resources. Some experience support within a harmonious relationship with access to emotional and social resources that facilitates their adaptation in a difficult situation. For other mothers who have other life-stresses, such as financial strain and relationships problems the stress they experience may stretch them to breaking point. Along with pre-existing life stresses, the stress and anxiety associated with the diagnosis of congenital heart disease is likely to negatively affect attention and memory (McEwen & Gianaros, 2010).

Furthermore, stress and anxiety can further escalate when information is not well understood. Highlighting this, in a longitudinal study of mothers who were at a high and low risk of stress Cerezo, Trenado, & Pons-Salvador (2006) examined, how mothers from both groups responded to, and provided care for their infants. Not surprisingly, results showed that mothers in the high-risk group for stress were slower to respond to their babies needs in comparison to the low-risk for stress group. While this study focused on healthy infants, results demonstrated altered responses by mothers to their babies who were affected by stress. It is likely that these responses would be more pronounced when a child is seriously ill.

The remainder of this section will review evidence for additional factors that are likely to enhance or detract from a mother's capacity to understand nursing and medical information. These additional factors are: the mother's level of education, self-efficacy, and health literacy; the mother's mental health; and general family life-stress.

The mother's level of education, self-efficacy, and health literacy

Consideration of a mother's level of education alone may not give a clear indication of her capacity to hear and understand important health information. While it is agreed that education is a proxy measure for health literacy, other characteristics, such as maternal skill and experience can influence how mothers understand information (Kendall & Tallon, 2011). Despite a mother's educational attainment, it has been long known that health knowledge does not necessarily translate into health behaviour. For example; it has been widely known that demonstration of knowledge about healthy diet, is often not reflected in corresponding eating behaviours (Povey et.al, 1998); and inequalities in alcohol related knowledge, behaviours and attitudes are also well known (Shelton & Savell, 2011). With relevance to parents of sick children, a more recent qualitative examination of 27 parents of chronically ill children found that their information needs were complex and not always appreciated by healthcare staff. Interestingly while most parents in this study sought out information about their child, it was found that some resisted information for fear of a negative impact (Hummelinck, 2005).

Mothers' responses to important information are likely to vary. Research findings show that mothers who score moderate and high levels of confidence and self-efficacy demonstrate higher sensitivity towards their infants needs than those who score lower (Donovan, Taylor, & Leavitt, 2007). There is also evidence that personal experience and beliefs are influential in times of adaptation (Lau-Walker, 2006). For example, a mother who has cared for younger siblings and actively participated in household responsibilities or cultural practices as part of a large family may have feel more confident than a mother who has not. Additionally, there is evidence that self-efficacy and communication skills support parenting (Tracy, 2006).

These qualities of confidence and acceptance are important. Collectively, education, self-efficacy, communication and motivation are identified as key qualities in understanding health information, also known as health literacy (Jordan, Buchbinder, & Osborne, 2010). A mother who lacks confidence in her maternal role may experience additional stress and anxiety when information is not understood. Equally, this additional stress and anxiety may further reduce her confidence in her role as a mother, making it somewhat of a vicious cycle. It is very important for nurses to consider maternal education, self-efficacy and health literacy collectively in

practice in order to provide more accurate indication of a mother's capacity to understand and provide appropriate care for her child.

Family life-stress and financial problems

As suggested earlier, other stresses such as financial burden may exacerbate parents' experiences of stress affecting how they manage and care for their seriously ill children. Preoccupation about financial worries associated with hospitalisation is likely to detract from accurately interpreting health information (Heck, 2000). Attending the hospital setting alone can generate significant additional costs and worry (Etchegary & Perrier, 2007; Shattuck, 2008). In a qualitative examination of stress associated with financial costs to families of children with congenital heart disease attending hospital, Connor (2010) found that the complexity of the disease, the level of socioeconomic advantage and higher levels of stress were associated with greater financial costs, emotional strain and more financial burden to family members. The study concluded that overall, costs were often identified as a considerable source of stress and emotional burden by families and called for early nursing attention to assist parents managing in the hospital environment. This study, while not conducted in Australia, remains relevant as it illustrates the impact of living costs such as accommodation, food and lost wages when attending hospital. This is particularly relevant in Western Australia as mentioned previously, many families are required to travel long distances to receive specialist health care (Government of Western Australia, Department of Health, 2012) The financial strain and disruption to family functioning can be a significant source of additional stress and anxiety for parents making it difficult for them to give their full attention to new information.

A diagnosis of congenital heart disease is also likely to be associated with parental anxiety. There is research supporting the significant effects anxiety can have on maternal child interaction. In a cross sectional control study by Lawoko and Soares (2002), the maternal attachment of 112 mothers of children with congenital heart disease was compared to 293 mothers of healthy children. Distress and hopelessness were measured using validated scales for depression, anxiety and somatisation which included areas such as loss of vitality, suicidal thoughts, gastrointestinal and cardiovascular symptoms and feelings of nervousness and fear. Results found a higher risk of distress and hopelessness among the mothers of children affected by

heart disease compared to those with healthy children. Also of concern, according to Lawoko and Soares (2002), the levels of distress and hopelessness were found to exceed the norms for depression acceptable at a psychiatric outpatient department in this study. These results highlight additional vulnerability of mothers whose children are affected by heart disease. The stress, anxiety and depression experienced by some mothers can make it very difficult for them to interpret new and often complex information about their child's condition and care.

Mother's mental health

Some mothers may already be predisposed to anxiety and/or depression regardless of their child's health. There is considerable literature examining the impact of anxiety and depression on maternal attachment with consequences for the child's long-term emotional and developmental health (Atkinson, et al., 2000; Dickstein, Seifer, et al., 2009). It is widely accepted that when a child experiences insecure attachment the mother is less sensitive to the baby's needs (Cerezo, Trenado & Pons-Salvador 2006). It is also well known that when a mother is unable to respond appropriately to her baby's cues it is likely to affect the quality of care she is able to provide (Howard et al., 2011). Important relationships between maternal attachment and depression were illustrated in a prospective study by McMahon, Trapolini, and Barnett (2008). In this study, mothers were found to be seven times more likely to report ongoing depression in a sample examining the attachment style of 172 mothers with previous depression. The ongoing psychological functioning of the child is also important as exemplified by Berant, Mikulincer and Shaver, (2008) in a prospective study examining the long-term effects of attachment insecurities in 63 mothers. Results showed that mothers' early attachment insecurities were associated with their children's emotional problems and poor self-image at seven years of age. This study is particularly relevant as the participants were all mothers of children with congenital heart disease. In similar studies examination of a mother's mood, cognition and affect showed reduced maternal sensitivity and response to infants needs and reduced maternal capacity to provide appropriate and timely care to her infant (Gartstein, 2009; Ingram & Smith, 2008; Ingram, Trenary, Odom, Berry, & Nelson, 2007), Notably, the majority of these studies are related to healthy infants and children. When a mother is anxious or depressed, it is likely to affect how she relates to and cares for her child. It could therefore be anticipated that symptoms in

mothers with pre-existing depression, whose children are seriously ill, could be more pronounced, affecting their capacity to manage appropriately in the long-term. These findings support the importance of nursing attention to maternal attachment as an indication of psychological wellbeing of the child and mother (Dickstein, Seifer & Albus, 2009).

A mother's mental health is therefore very important when determining how she will take care of her seriously ill child (Berant, Mikulincer, & Florian, 2001). It is agreed that mental health problems can significantly affect the quality of parenting a child receives. In a literature review by Dix & Meunier (2009) the mechanisms that cause depressive symptoms to undermine parenting were explored. Here 152 relevant studies were reviewed and the impact of maternal depressive symptoms on parenting was examined. The processes of cognition, affect and motivation were considered. An action controlled framework was developed for this sample to organise how depressive signs could impact parenting. Findings suggested that depressive symptoms impacted parenting particularly in relation to parental attention, memory and reduced self-efficacy. These findings illustrate important effects emotional and mental health problems can have on a mother's understanding, capacity to remember information and her decision making. This is particularly important because mothers of seriously ill children who are affected by additional stress, anxiety and/or depression are likely to require much support from nurses to help them understand their child's condition and relate information appropriately to the child's care in hospital.

Summary

This section examined how stress, anxiety and depression can affect the attention and memory of mothers of seriously ill children. The influence of parental resources, such as education and good mental health in supporting the mother to understand information was discussed. The impact of financial burden and life stresses were examined in relation to a mother's development of knowledge and understanding about her seriously ill child's condition and care in the hospital setting. Implications for the nurse were considered.

Summary of literature review

Bioecological theory and the resources conceptual framework were introduced. Findings examined in this review of the literature support the view that children with congenital heart disease in need of surgery are at increased risk for neurodevelopmental problems. These children need the best care possible from their parents to minimise complications and maximise long term health and developmental outcomes. Mothers must understand their children's needs well in order to provide the appropriate care. However, this may be difficult for those mothers who experience additional stress, anxiety, depression or a lack of social support. The underlying theories examined in this review of the literature guide data collection and are important for future nursing practice in terms of assessing a family's psychosocial situation on their first presentation in the clinical setting. Findings in this review of the literature supports the key role nurses play in supporting the families they care for.

METHODOLOGY

Study design

This chapter describes the study design, research enquiry and characteristics of the participants for this project. The reliability and validity of instruments used, ethical considerations and statistical methods used for the purposes of this research project are also presented.

Aims and Objectives of the Study

As outlined in the Introduction the aims of this study are two-fold. Firstly, to develop an instrument that may potentially serve as an indicator for nursing intervention by effectively measuring mothers knowledge and understanding of their child's heart surgery and care. Secondly, to examine the effect of psychosocial factors including stress, anxiety, depression, and social support on the participating mothers' knowledge and understanding of their children's heart disease and care at the time of their child's heart surgery using the instrument being developed.

Research Questions

The following research questions were developed:

1. Is it possible to measure a mother's knowledge and understanding of her child's cardiac surgery and subsequent care using an instrument specifically developed for this purpose?
2. Are heightened levels of stress and anxiety and lower levels of social support associated with lower levels of maternal knowledge and understanding at the time of surgery?

Related Hypotheses

1. The instrument that is developed to measure mothers' knowledge and understanding will have adequate content and construct validity, and internal consistency.
2. Heightened levels of stress and anxiety, and lower levels of social support, will be associated with lower levels of maternal knowledge and understanding at the time of surgery when child and maternal demographics are accounted for.

In this project, quantitative methods were applied to explore factors that influence mothers' knowledge and understanding of their children's heart condition and

appropriate care at the time of surgery. Descriptive analyses of socio-demographic and psychosocial factors were completed while a measure for maternal knowledge and understanding of her child's heart disease at the time of surgery was developed. Validation of this measure was pursued for application within the paediatric cardiothoracic environment as a nursing predictor for early intervention. Relationships between socio-demographic and psychosocial factors and maternal knowledge and understanding were examined using bivariate analysis, one way analysis of variance, and multiple regression analysis.

Participants

Mothers' with children scheduled for heart surgery at The Children's Cardiac Centre, PMH between August 2008 and April 2010 were invited to participate. Cardiac surgery was defined as open or closed cardiothoracic surgery requiring scheduled admission to the paediatric intensive care unit (PICU). Previous records presented at The Annual Cardiac Surgical Review at PMH for the years 2005 and 2006 found 120 and 140 operations respectively were performed each year (PMH, 2006). It was therefore anticipated that 110 – 130 mothers would be eligible to participate during the data collection period. In order to avoid a Type I error, a power analysis was performed prior to data collection. This was calculated based on the assumption that 50% of mothers with anxiety or psychosocial difficulties would have reduced knowledge and understanding compared with 20 per cent of those with no difficulties. On this basis the study would have 80 per cent power to detect a difference in values with .05 probability of incorrectly rejecting the null hypothesis if 90 mothers participated.

In October 2008, two months into the data collection period, a hospital review of cardiothoracic surgical services at PMH commenced. As a consequence, complex neonatal surgery was redirected interstate resulting in a reduction of cardiac operations performed at the hospital. Following consideration for these changes, mothers travelling interstate were also invited to participate when possible. To accommodate the potential reduction in sample size, the data collection period was extended by eight months from August 2009 until April 2010.

Procedure

Mothers received a written invitation included in the mailed correspondence from the hospital outlining the preoperative and admission arrangements. Those interested

responded by returning a completed form in the provided self-addressed stamped envelope (Appendix A). At the time of the pre-operative visit, these mothers received an information sheet describing the study in more detail with the opportunity to ask questions then or later by telephone. Finally mothers who agreed to participate were required to sign the accompanying consent form either at the time of this visit or admission to hospital (Appendix B).

Participating mothers were invited to complete a questionnaire (Appendix C). The questionnaire was divided into four sections A - D. Section A contained questions about the child: date of birth, duration of pregnancy, birth weight, time of diagnosis, whether or not admission to a neonatal unit was required, and whether or not additional health problems were identified. Section B contained information about the mother: her age, relationship status, education, occupation, family structure, and financial status. These characteristics were categorised according to the Australian Bureau of Statistics (ABS, 2006). Section C contained two validated instruments; one measuring maternal depression, anxiety, and stress and the other measuring levels of maternal social support. Section D of the questionnaire contained a consensual instrument measuring maternal knowledge and understanding which was developed for the purposes of this research.

Measures used in the study

Characteristics of the child

The degree of complexity of the child's surgical procedure was recorded using the Risk Adjustment for Cardiac Surgery Score (RACHS) (Jenkins, 2004). The RACHS score categorises the range of surgical procedures in order of complexity into six levels from least to most complex. Additional risk factors such as prematurity and other health problems are also accounted for. RACHS was validated in two independent populations and was found to have good predictive value (Larsen, Jacobsen, Johnsen, Hansen & Hjordal, 2005). Further validation of the RACHS was supported in a study of 13,675 operations comparing the RACHS with the alternate Aristotle Basic Complexity Score (Al-Radi et al., 2007). Both scores showed high association with in hospital mortality and length of stay. However, the predictive value of the RACHS was found to be significantly higher than the Aristotle Score. During the period of data collection the operations performed on the participating children fell between Category 1 – 4 only. A variable was derived to identify

children in one of four categories (least complex; some complexity; more complexity; and most complex).

The Depression, Anxiety, and Stress Scale (DASS)

The 42 item DASS self-report inventory measures depression, anxiety, and stress. This instrument, developed and validated by Lovibond and Lovibond (1995), uses a 4-point Likert score. Reliability of the three scales is considered adequate and test-retest reliability is also considered to be adequate with Cronbach's alpha of .71 for depression, .79 for anxiety and .81 for stress (Brown et al., 1997). Exploratory and confirmatory factor analyses sustained the proposition of the three factors ($p < .05$; Brown et al., 1997). The DASS instrument correlates .81 with the Beck Anxiety Inventory (BAI), and the DASS Depression scale correlates .74 with the Beck Depression Scale (BDI). Continuous as well as categorical summary variables were derived to indicate the range of stress, anxiety and depression experienced from normal to severe.

The Maternal Social Support Index (MSSI)

The MSSI measuring maternal support is a 21-item questionnaire designed to assess qualitative and quantitative aspects of a mother's social support (Pascoe et al. 1981). The MSSI is comprised of seven sections, the first of which is a 10-item inventory of questions regarding the division of tasks at home including home maintenance, housework, shopping, and caring for and disciplining the children. A three point Likert-style response is used to determine the level of support a mother has with the various domestic activities. A further section asks about a mother's access to support including contact with relatives, someone to talk to, people she can count in her family or friendship network as well as rating satisfaction with partner support. The MSSI has been shown to have a test-retest correlation of .72 ($p < 0.001$) over six to eight weeks, and coefficient alphas ranging from .60 to .63 across the three samples, denoting moderate internal consistency (Pascoe, Ialanga, Horn, Reinhart, & Perradatto, 1988). Categorical (none, some, a lot), and binary variables (happy, not happy) were derived for different items and a continuous summary variable was derived for the overall score.

The Maternal Knowledge and Understanding Scale (MKUS)

The MKUS was based on the Congenital Heart Disease Home Care Manual established at the Department of Cardiology, Arkansas Children's Hospital, Little Rock, Arkansas, USA, by Pye and Green, (2003). The learning areas for parents identified in Congenital Heart Disease Home Care Manual (Pye & Green, 2003) formed the basis of the MKUS. These learning areas included; defect specific information, feeding and nutrition, administration of medications, care of the incision wound, identification of complications, and, health maintenance. While this work was completed in 2003, the content was considered current and relevant as a comprehensive review of the areas important when providing information to parents following their child's paediatric cardiac surgery. Fifteen questions were included in Section D of the Questionnaire (Appendix), however, Question 15 asking if the mother know when the child's follow up appointment was excluded from analysis as this was not often scheduled at the time mothers were completing the questionnaire. The remaining 14 questions were developed around these learning areas. Three questions were reversed to encourage participants to read every question carefully. The questions were reviewed for readability and relevance to current nursing practice by nursing peers working with families and children experiencing congenital heart disease both locally and nationally (Appendix C, Section D).

Statistical Analysis

Data were recorded and analysed using Statistical Package for Social Sciences Version 16 (SPSS, 2007). Descriptive statistics were calculated to examine prevalence of maternal and child characteristics and demographic data. As data analysis assumes a normal distribution, it was important this was examined (Tabachnick & Fidell, 2007). In order for the data to resemble normal distribution, data were transformed and analysis was performed on transformed and untransformed data. Results for analysis of transformed and untransformed data were similar. These findings supported a Type I or Type II error related to the assumption of normality was unlikely. However, true normality is rare in health, education and psychology (Micceri, 1989). Therefore, this level of complexity was not added to the data analysis. In addition, categorical variables were derived for anxiety, stress and depression scores. Participants were classified as experiencing these states "not at all", "to a mild degree", "to a moderate degree", or "to a severe degree". Binary

variables that identified participants as either having anxiety, stress, and depression or not were derived using cut-offs suggested by the authors of the DASS.

Independent *t* tests and one way analyses of variance with Bonferroni correction were undertaken to explore the relationships between maternal and child characteristics as independent variables, and the presence of anxiety, stress, depression, and social support as dependent variables. While the Bonferroni test can overcorrect for Type I error it remains the most commonly used test to compare categories within a variable as it is flexible and can be applied to any statistical test (Allen & Bennett, 2010). Pearson's correlations were used to illustrate high correlations between anxiety, stress, and depression.

Analysis of the first 26 questionnaires was a preliminary analysis to establish face and content validity. Responses showed that information was perceived similarly amongst the mothers, however there was little variability across the original 4-point Likert scale. In order to enhance sensitivity of the instrument, the 4-point scale was therefore replaced by a 10-point scale for the remainder of the data collection.

Following data collection, reliability analysis of the MKUS was undertaken using Cronbach's alpha. Of the 14 questions measuring maternal knowledge and understanding, eight were found to have reasonable correlation with a Cronbach's alpha of .78 and were therefore selected for final analyses. The MKUS with eight questions / statements and a 10-point Likert scale, indicated a score between one to ten, with one representing the least agreement and ten representing most agreement with the relevant statement.

This gave a continuous score for MKUS ranging from 0 - 80.

It was found that MKUS scores were not normally distributed. Because the scale had not been previously used, normality could not be assumed across the general population (Tabachnick & Fidell, 2007). Therefore, non-parametric analysis was performed to examine relationships between maternal and child demographics as independent variables and the MKUS score as the dependent variable. Binary variables were created from maternal categorical variables in order to conduct non-parametric testing with MKU score as the outcome variable. The MKU score variable was transformed to a log variable to correct for normal distribution. Non-parametric tests were performed using Mann-Whitney U test for comparison of dichotomous variables and the Kruska-Wallis Test when examining relationships

between variables with more than two categories. Therefore the Mann-Whitney test was used as the equivalent of the independent sample t-test when the data is not normally distributed (Hart, A. 2000). The Kruskal-Wallis test was used for non-parametric analysis of variables with more than two categories (Tabachnick & Fidell, 2007).

Finally, Multiple Linear Regression was used to identify the independent relationship between all maternal and child variables, including anxiety, stress, depression, and social support and the MKUS score. For reasons stated previously, a log-linear transformation was performed on the MKUS data prior to regression modelling.

Ethical considerations

This study was approved by the Human Research Ethics Committee at Curtin University and the PMH Ethics Committee. To avoid any undue influence by the researcher who was working within The Children's Cardiac Centre at PMH at the time, invitation letters were included with preoperative and admission information sent from the Medical Director. Mothers were also informed that the care their child received would not be affected by their choice to participate or not.

To ensure confidentiality, participants were assigned study numbers recorded on the questionnaires. A master list of participants was kept in a locked filing cabinet in a secure office at the Children's Cardiac Centre for the duration of the study. No other hospital staff members were given access to this research information. The researcher was not able to link personal information to questionnaire information. RACHS information was obtained by the researcher from CCC surgical database using the child's date of birth and date of surgical procedure. The child's personal information was available to the researcher, but this information was not accessed. Hardcopy questionnaire information was kept in a locked filing cabinet in a locked office and electronic information protected by user password. Participants were asked to contact one of the study supervisors in the event of experiencing any concerns related to participation or content of questionnaire where appropriate support and access to specialist support would be arranged if required. Following completion of the study electronic and hardcopy data including copies of questionnaires will continue to be stored for a minimum of seven years.

RESULTS

Introduction

In this chapter, response rates, participating child and maternal demographics, the internal consistency of the consensual instrument employed to measure maternal knowledge and understanding, and sociodemographic and psychosocial characteristics found to influence maternal knowledge and understanding are presented. Bivariate analyses using appropriate statistical tests accounting for normal distribution, continuous, categorical and binary variables are reported. Finally, the results of multiple regression modeling are displayed and discussed.

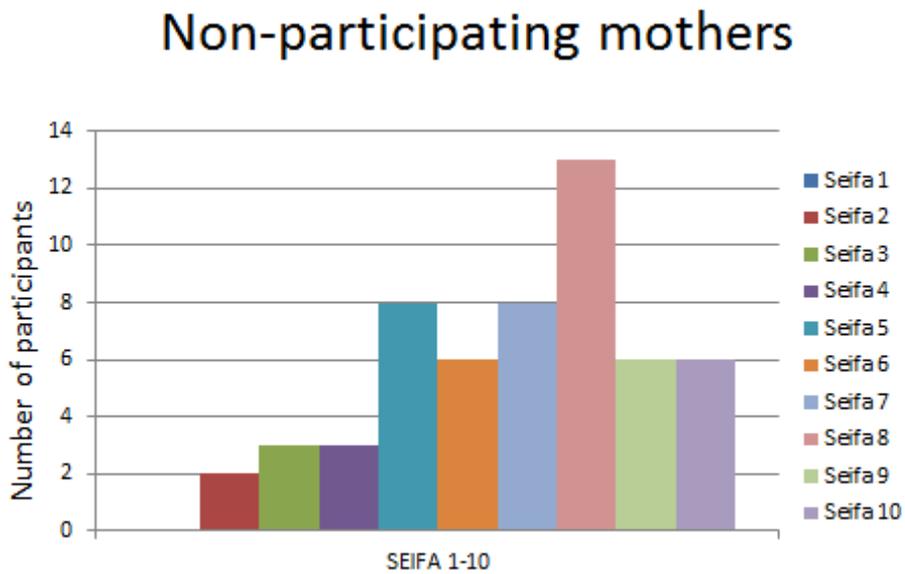
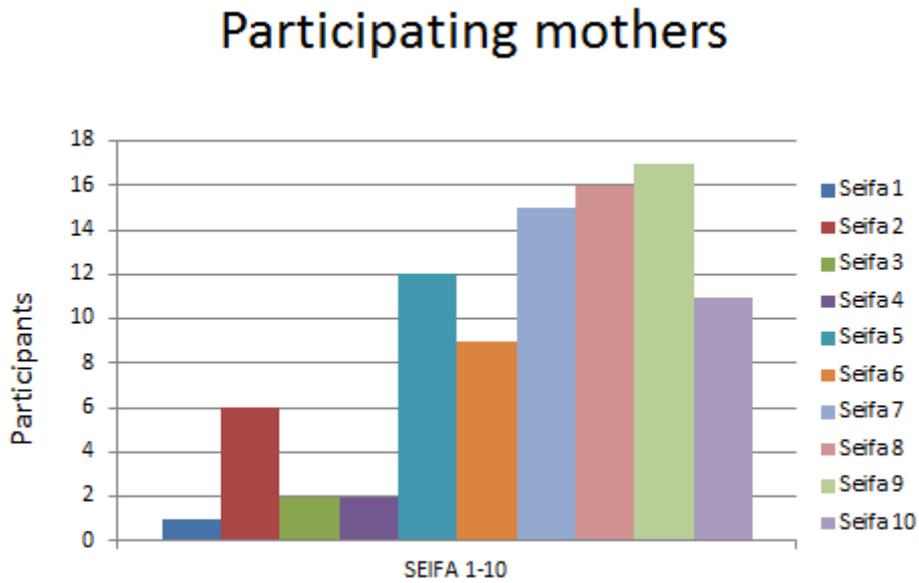
Response rates

Ninety-one participating mothers completed a questionnaire at the time of their child's cardiac surgery from August 2008 until April 2010. During this time a total of 166 infants and children underwent cardiac surgery at PMH. Of these, 148 mothers whose children required open or closed surgical intervention were invited to participate. Those not invited included 16 mothers who were not accessible to the researcher because their children underwent emergency cardiac surgery out of hours, and two fathers who were single parents. Of the 148 mothers invited to participate 93 consented and 91 returned completed questionnaires giving a response rate of 61%.

Characteristics of participants versus non-participants

The proportion of participating and non-participating mothers who live in more advantaged and more disadvantaged geographical areas is presented in Figures 4.1 and 4.2 For this the Socio-Economic Index for Areas (SEIFA) was applied. The SEIFA is summary of the following four index measures: Relative Socio-economic Disadvantage (IRD); Socio-economic Advantage and Disadvantage (IRSAD); Economic Resources (IER); and Education and Occupation (IEO) (Australian Bureau of Statistics, 2006). The SEIFA ranges from 1-10 with one representing the area with least advantage and a SEIFA of ten representing a geographical area representative of most advantage. A statistically significant difference was found between the groups with study participants more likely to live a more advantaged area ($t = 27.08$ $p = 0.04$).

Figure 4.1
Comparison of Participating and non-participating mothers using
socioeconomic index for areas



Characteristics of participants

The Mother

Ninety-one mothers completed a questionnaire. Prevalence rates for maternal sociodemographic characteristics are presented in Table 4.1.

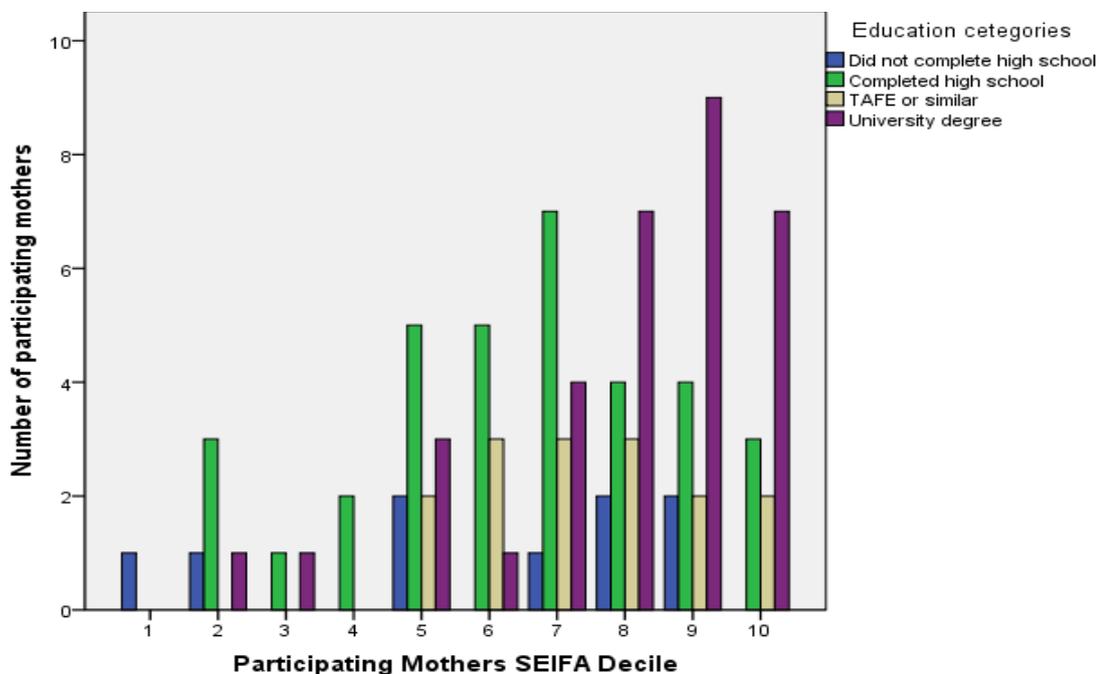
Table 4.1
Characteristics of participating mothers

Mother	<i>n</i>	%
English spoken at home	83	91.2
Language other than English at home	8	8.8
Age		
19 - 29	24	26.4
30 - 40 years	53	58.2
41 + years	14	15.4
Education		
Did not complete High School	9	9.9
Completed High School	34	37.3
TAFE / Apprenticeship	15	16.5
University Degree	33	36.3
Work force		
Full or part time work	46	50.5
Not working outside the home	45	49.5
Occupation		
Professional / Academic	17	18.7
Health / Teaching	6	6.6
Trade	5	5.5
Senior Clerical	15	16.5
Sales	1	1.1
Labour / Cleaning	2	2.2
Not working outside the home	45	49.4
Relationship		
Single divorced / widowed	23	25.8
Living with someone	68	74.2
Financial situation		
Not enough money - week to week	24	26.7
A little left over week by week but spent it	52	56.7
We can save regularly	14	15.5
	1*	1.1

*Missing excluded from analysis

Table 4.1 shows that maternal age ranged from 19 – 54 years with 24 (26.4%) aged between 19 – 30 years, 53 (58.2%) between the age of 30 and 40, and 14 (15.4%) over the age of 40 years. English was spoken in 83 (91.2%) maternal homes with 8 (8.8%) mothers speaking Arabic, Hindi, Shona, Spanish, Tamil, Thai, Tolu and Vietnamese respectively (see Table 4.1). Table 4.1 also shows that 9 mothers (9.9%) did not complete high school, 34 (37.3%) completed Year 12, 15 (16.4%) attended TAFE or completed an apprenticeship, and 33 (36.3%) held a university degree. The relationship between education and geographical area of residence is shown in Figure 4.2. Mothers with more education were more likely to live in an advantaged geographical area ($F = 2.722$; $p = 0.035$). Forty six (50.5%) of the mothers reported they worked full or part time while 45 (49.5%) did not work outside the home (Table 4.1). At the time of data collection, 68 (74.7%) mothers were living in a relationship and 23 (25.3%) were single, separated, divorced or widowed (Table 4.1). Lastly, Table 4.1 shows that 24 (26.3%) participants did not have enough money from week to week, 51 (56.6%) had a little money over from week to week but spent it and 14 (15.6%) reported they were able to save regularly.

Figure 4.2
Relationship between SEIFA and maternal education categories



The Child:

Of the 91 children, 59 (64.8%) were male and 32 (35.2%) female ranging in age range from two days to 15 years of age (see Table 4.2).

Table 4.2
Characteristics of participating children

Characteristics	n	%
Male	59	64.8
Female	32	35.2
Age		
< 1 year	29	31.8
1 – 3 years	17	18.7
> 3 years	45	49.5
Gestation		
Term	74	81.3
Preterm	17	18.7
Pregnancy		
Single	87	95
Twin	4	5
Admission to NNU		
No	56	61.5
Yes	35	38.5
Time of Diagnosis		
Antenatal period	23	25.3
At birth	40	43.9
After birth	28	30.8
RACHS		
Least complexity	20	21.9
Some complexity	44	48.4
More – most complexity	27	29.7
Additional Health Problems		
Nil	70	76.9
Mild	7	7.7
Major	14	15.4

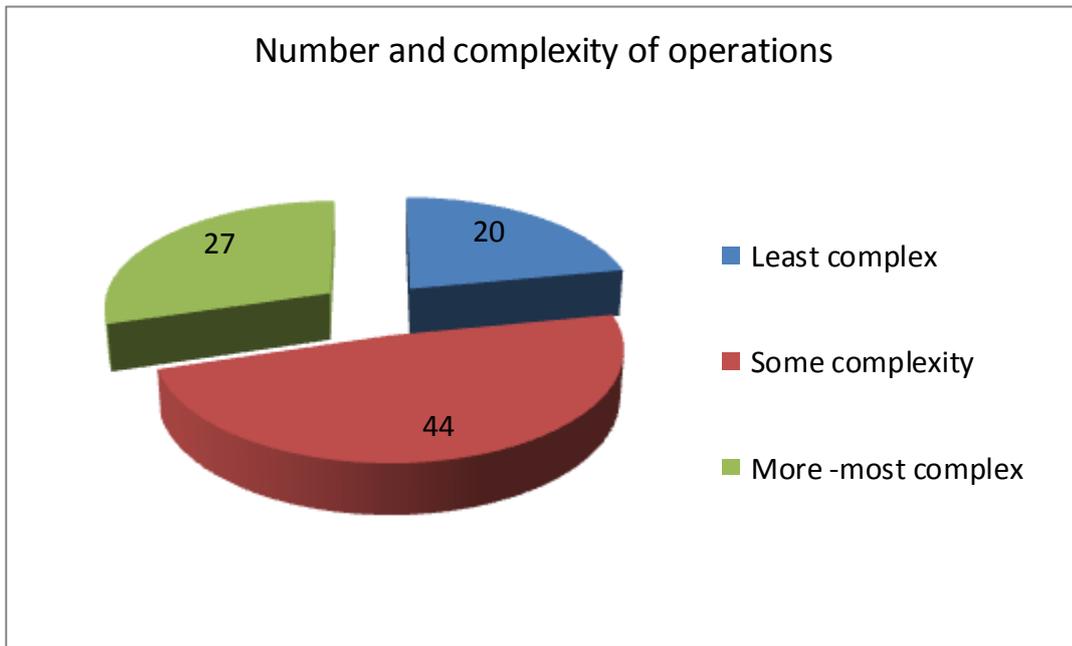
The mean age was 32 months and standard deviation 16 months and two weeks. Negative skewness of -1.38 supported the distribution of age categories with 29 (31.8%) infants less than one year of age, 17 (18.7%) were between 1 and 3 years of age, and, 45 (49.5%) children over the age of three years of age (Table 2). Birth weights reported ranged from 1350gm – 4718gm with a mean of 3140gm and standard deviation of 602gm. Table 2 shows that seventy-four (81.3%) of the children were born at term with 17 (18.7%) preterm, following single pregnancy in 87 cases (95.6%) and twin pregnancy in four (4.4%) cases.

Thirty-five (38.5%) infants required admission to the Neonatal Unit following birth while 56 (61.5%) remained in the care of their mother (Table 2). Table 2 also shows the time of diagnosis with congenital heart disease was diagnosed in the antenatal period in 23 pregnancies (25.3%). Forty infants (43.9%) were diagnosed at the time of birth and 28 (30.8%) were diagnosed later. All children required cardiac surgical intervention. The surgical procedures performed on participating infants and children were organized using the Risk Adjustment for Congenital Heart Surgery (RACHS) (Larsen, Jacobsen, Johnsen, Hansen and Hjordal, 2005).

The presence of additional health problems is shown on Table 4.2 with 70 (76.9%) children congenital heart disease was the isolated diagnosis, while seven (7.7%) reported minor health problems including eczema and asthma managed by the family GP, and 14 (15.4%) had major additional health problems requiring specialist attention including congenital abnormalities such as Down Syndrome, Di George Syndrome and chronic lung disease associated with prematurity.

Table 2 also shows the operations performed on the children designated according to complexity as: Twenty (21.9%) least complex, 44 (49.4%) some complexity, and 27 (29.7%) more complex operations were allocated respectively with no participants allocated to the most complex categories five or six at the time of data collection. The number and distribution of procedure complexity is illustrated in Figure 4.2.

Figure 4.2
RACHS and number of operations



Consistency of instruments

The validated Depression, Anxiety and Stress Scale (DASS) instrument was used, along with the validated Maternal Social Support Index Score (MSSI).

Correlation between Stress, Anxiety and Depression

Not surprisingly the Stress, Anxiety and Depression scores were found to be highly correlated showing statistical significance with a *p* value of less than 0.05. This is shown on Table 4.3.

Table 4.3

Correlation between Stress, Anxiety, Depression

		Stress	Anxiety	Depression
Stress	Pearson Correlation	1	.493**	.701**
	Sig. (2 tailed) n (91)		.000	.000
Anxiety	Pearson Correlation	.493**	1	.468**
	Sig. (2 tailed) N (91)	.000	.	.000
Depression	Pearson Correlation	.701**	.468**	1
	Sig. (2 tailed) N (9)	.000	.000	

** Correlation is significant at the 0.01 level of significance

Table 4.4 shows the levels of stress, anxiety and depression reported. Sixty-four (70.3%) of the mothers scored within the normal range for stress, while 13 (14.3%) reported mild stress, 8 (8.8%) moderate and 6 (6.6%) reported experiencing severe levels of stress (Table 4.4). Sixty (72.5%) participating mothers scored within normal limits for anxiety with 6 (6.6%), 14 (15.4%) and 5 (5.5%) reporting mild, moderate and severe levels respectively. Twenty percent of participating mothers reported some level of depression. Eleven (12.1%) reported mild, 6 (6.6%) moderate and 3 (3.3%) severe depression respectively (see Table 4.4).

Table 4.4

Maternal Depression, Anxiety and Stress reported.

Levels	<u>Stress</u>			<u>Anxiety</u>			<u>Depression</u>		
	<i>range</i>	n	%	<i>range</i>	n	%	<i>range</i>	n	%
Normal	<i>0-14</i>	64	70.3	<i>0-7</i>	60	72.5	<i>0-7</i>	71	78
Mild	<i>15-18</i>	13	14.3	<i>8-9</i>	6	6.6	<i>8-9</i>	11	12
Moderate	<i>19-25</i>	8	8.8	<i>10-14</i>	14	15.4	<i>10-14</i>	6	6.6
Severe	<i>26-33</i>	6	6.6	<i>15-19</i>	5	5.5	<i>15-19</i>	3	3.4
Total		91			91			91	

Figure 4.5 shows indicators for maternal support using the MSSSI. The majority of participating mothers, 85 (93.4%) reported they had support with home duties including housekeeping and home maintenance, shopping and caring for and disciplining the children had a score of 30 using the MSSSI (see Figure 4.5).

Figure 4.5
Histogram MSSSI score – help with home chores

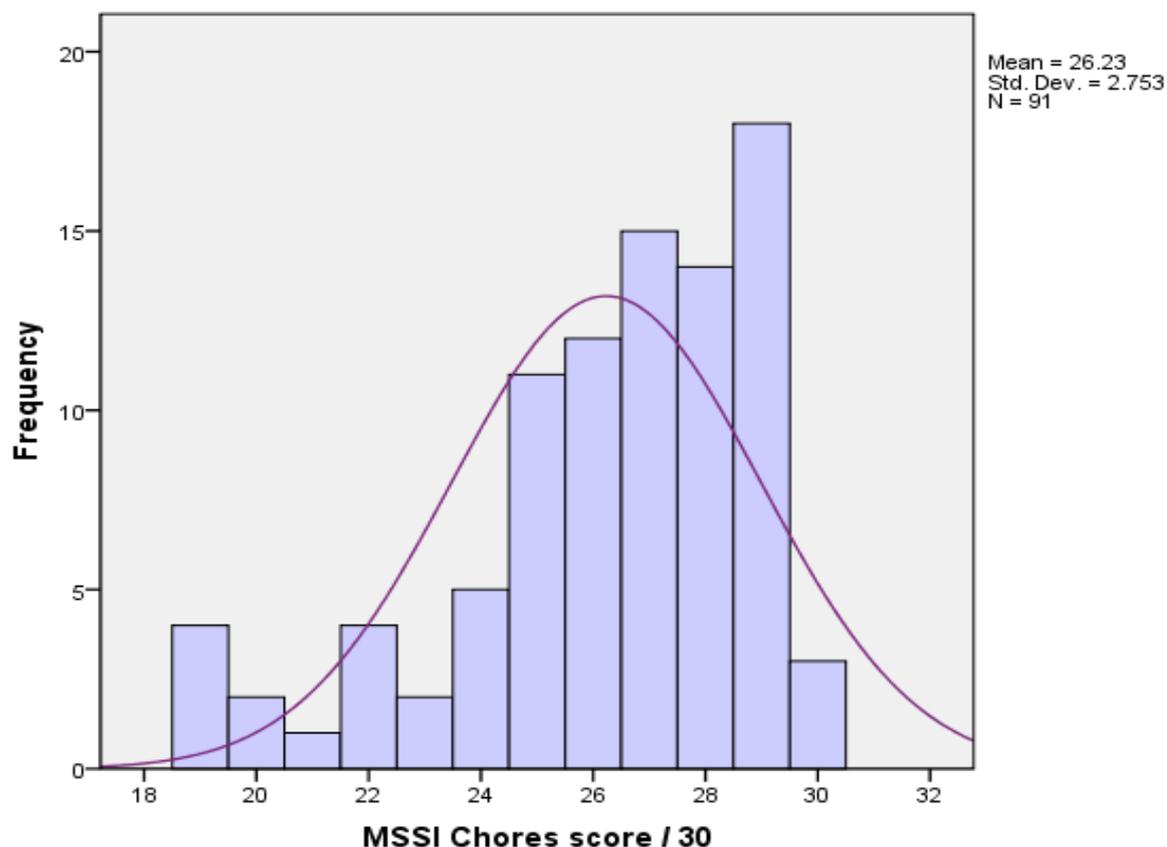


Table 4.5 illustrates maternal social support indicators in more detail. Forty five (49.5%) mothers reported they did not see their relatives at all or enough. Most mothers 85 (93.4%) indicated they had someone to talk to other than their partner and 84 (92.3%) of mothers reported they had two or more people to count in when assistance was needed (Table 4.5). However, 27 mothers (30%) reported they either had no support or were unhappy with the support they received (see Table 4.5).

Table 4.5**Maternal social support indicators**

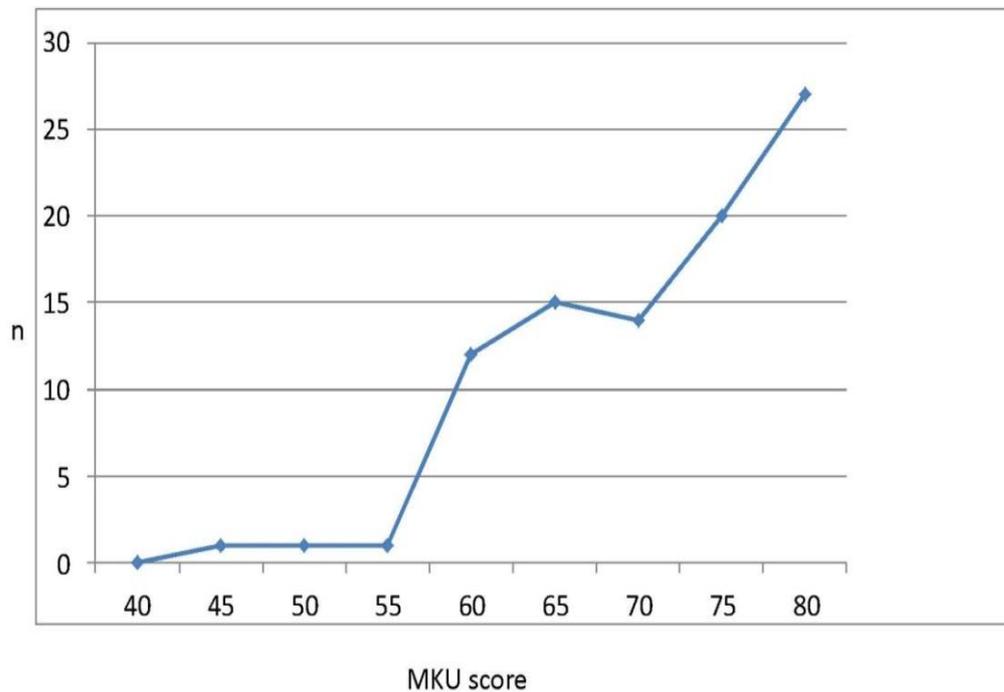
Social factors	n	%
Relatives seen		
No relatives seen	12	13.2
Not often enough	45	49.5
Often enough	34	37.4
	91	
People you can count on		
One person	7	7.7
Two people	10	11.0
Three or more people	74	81.3
	91	
Partner support		
No support or not happy with support	27	29.7
Partner support and happy	64	70.3
	91	
Outside talks		
No outside talks or not happy with talks	9	6.6
Outside talks and happy	85	93.4
	91	100

Consensual instrument to measure MKU

The lowest to highest MKUS scores recorded ranged from 44 as the lowest to 80 as the highest (Figure 4.6). The mean score was 69.57 and standard deviation 7.9 with skewness of -.645 and kurtosis -.078. (Figure 4.6).

Figure 4.6
MKUS score

Mean 69.57
Mode 64
Median 71
SD 7.926
Skewness -.645
Kurtosis -.078



This consensual instrument measuring maternal knowledge and understanding was in the form of a questionnaire which contained 14 questions requesting agreement or disagreement using a 10-Likert-scale point. Eight statements within this instrument were found to have a high correlation and Cronbach's alpha of .78 and were therefore selected to make up the MKUS instrument for analysis. Using the 10-point Likert-scale confirmed 80 as the highest score which can be seen in Table 4.6. The instrument's items as well as mean scores and standard deviation can also be seen in Table 4.6. Table 4.6 shows that questions two (2), three (3), and four (4) were about care provided in ICU. Here mean scores and standard deviations suggested some certainty with 9.07 and 1.489 (2), 9.15 and 1.105 (3), and 9.1 and 1.325 (4) reported. Responses to questions five (5) and six (6), related to care received on the Ward. These also indicated some certainty with mothers reporting scores and standard deviations of 8.86, and S.D. 1.697 for question five, and 9.03, and 1.286 for question six. However, responses to questions one (1), seven (7), and eight (8), which were related to explaining the child's needs to others, knowing the signs to look for, and who to call when concerned, indicated less certainty with mean scores and S.D. 8.34 and 1.558 (1), 8.33 and 1.955 (7), and 7.69 and 2.059. (See Table 4.6).

Table 4.6
MKUS statements

Statement – correlation Cronbach’s alpha .78	Range	Mean	SD
1. I can describe the long term benefits the surgery will bring to my child	<1 – 10>	8.35	1.558
2. My child will require the support of a ventilator (breathing tube) for a period of time following surgery	<1 – 10>	9.07	1.489
3. My child will be deeply sedated and will not respond to my cues immediately following the operation	<1 – 10>	9.15	1.105
4. My child will be allowed to recover at his/her own pace and have the breathing tube and drains removed accordingly	<1 – 10>	9.10	1.325
5. It is important my child’s dressing be kept dry and in place for a period of 10 days	<1 – 10>	8.86	1.697
6. As my child recovers on the Ward administering regular pain relief will be necessary	<1 – 10>	9.03	1.286
7. I know who to call in the event of any concern that may present itself before my child’s next appointment	<1 – 10>	8.33	1.955
8. I can explain to friends and family the signs in my child that will bring me to seek medical attention	<1 – 10>	7.69	2.059
Total Score	> 0	-	80 <

Bivariate Analysis

Non Parametric Testing

No relationships of significance were found comparing MKUS scores to maternal age, education, or financial factors (see Table 4.7). However, mothers who reported they did not see their relatives at all or enough scored lower in MKUS with a p value of 0.021 (Table 4.7). Similarly mothers who reported they had no one to talk to or were unhappy with talks they had reported a significantly lower MKUS score (p 0.047) (Table 4.7).

Table 4.7

Non parametric bivariate analysis – maternal characteristics and MKUS

Maternal indicators relationship with MKU log	Mann Whitney U	significance
Maternal Age		
19-29 compared to 30-40	132.000	.530
19-29 compared to over 40	130.500	.256
30-40 compared to over 40	378.000	.914
Maternal Education		
No Year 12 compared to completed Year 12	132.000	.530
No Year 12 compared to TAFE or similar	128.500	.539
No Year 12 compared to Degree	59.000	.612
Completed Year 12 compared to TAFE	575.500	.856
Completed Year 12 compared to Degree	255.500	.991
TAFE or similar compared to Degree	248.000	.991
Language spoken		
English compared with other language	290.000	.556
Relatives seen		
Not enough compared with seen regularly	669.500	.021*
Partner support		
Not enough compared enough support	1041.00	.124
Outside talks		
Nil/not enough talks vs. supportive talks	361.500	.047*

* p significant at .05

The findings of non-parametric testing examining relationships between child characteristics and MKUS did not show any significant relationships (See Table 4.8).

Table 4.8

Non parametric bivariate analysis – child characteristics and MKUS

Child indicators relationship with KU log	Mann Whitney U	Significance
Child Age		
Less than 1 year of age / 1-3 years	271.000	.577
Less than 1 year / older than 3 years	663.000	.907
1-3 years / older than 3 years	357.000	.693
Gender		
Male compared to female	890.000	.653
Gestation		
Term compared to preterm	464.000	.907
Time of diagnosis		
Before birth compared to after birth	834.000	.694
Admission to NNU		
Yes / No	885.500	.440
Additional health problems		
No additional health problems / minor	291.500	.409
No health problems / major	569.500	.339
Minor health problems / major	47.500	.911
RACHS		
Least complex compared with some	549.500	.391
Least complex compared with more /most	76.500	.858
Some complexity compared with more /most	270.500	.736

Parametric testing

Using stress, anxiety, depression, and maternal social support as independent binary variables and MKUS score as a continuous outcome variable mothers who scored higher in anxiety were found to score lower in MKUS with F statistic 2.315 and *p* value of .024. See Table 4.9.

Table 4.9
Independent t test - DASS, MSSSI and MKUS

DASS and MSSSI - independent variables		
MKUS score - continuous variable		
	t statistic	<i>p</i>
Stress	.938	.351
Anxiety	2.315	.024*
Depression	.804	.429
MSSSI	.181	.863

* *p* significant at 0.05

One way analysis of variance showed that mothers who reported not having enough money scored higher in anxiety with F statistic of 3.135 and *p* value.048. These findings are presented on Table 4.10.

Table 4.10
One way analysis between maternal and child factors and Stress, Anxiety, Depression
and Social Support

	Stress	Anxiety	Depression	MSSI
	F (p)	F (p)	F (p)	F (p)
SEIFA	1.344 (.171)	.869 (.685)	1.461 (.111)	.922 (.612)
Maternal Age in years	.113 (.893)	.988 (.376)	.250 (.780)	1.322 (.272)
Maternal Education	.312 (.869)	.411 (.746)	.562 (.691)	.360 (.780)
Financial situation Not enough A little over Can save regularly	2.158 (.122)	3.135 (0.48)*	2.337 (.103)	1.116 (.360)
Other health problems Nil Minor Major	1.148 (.322)	1.078 (.345)	.288 (.750)	.924 (.401)
RACHS Least complex Some complexity More - most	.964 (.386)	.625 (.537)	3.765 (.027)*	.092 (.912)
Time of diagnosis	.631 (.535)	.900 (.410)	.104 (.901)	3.335(.040)*

* *p* significant at <0.05

Table 4.11**Independent t test analysis between maternal and child factors and Stress, Anxiety, Depression and Social Support**

	Stress		Anxiety		Depression		MSSI	
	<i>t</i>	<i>p</i>	<i>t</i>	<i>p</i>	<i>t</i>	<i>p</i>	<i>t</i>	<i>p</i>
In workforce	.443	(.659)	.689	(.403)	.325	(.990)	.730	(.467)
English at home	.080	(.936)	-.304	(.196)	-1.399	(.165)	-.691	(.491)
Relationship								
Single	1.689	(.103)	1.468	(.154)	.957	(.341)	-1.986	(.050)*
Lives with partner								
Relatives seen	-.923	(.361)	-.993	(.325)	-1.143	(.295)	-.045	(.964)
Not at all or enough								
Sees relatives enough								
Outside talks	.449	(.655)	.282	(.585)	.493	(.623)	-2.565	(.046)*
No talks / not happy								
Talks and happy								

* *p* significant at <0.05

Table 4.10 shows bivariate analysis using DASS, MSSI scores as outcome variables to examine relationships with maternal binary variables. Mothers who were single and those who reported they had no support or were unhappy with the support they received scored lower in MSSI with a *p* value of .050 and .048 respectively. See Table 4.10.

Child variables were also examined using one way analysis and independent t tests (see Table 4.10). A significant relationship was found between maternal depression and the complexity of the child's operation with Bonferroni post hoc analysis showing that mothers of children requiring higher complexity surgical procedures scored higher levels of depression with F statistic 3.765 and *p* value .027. This is also seen on Table 4.10. A relationship was also found between maternal support and the time of their child's diagnosis with post hoc analysis of groups showing that this finding was consistent across values with mothers whose children were diagnosed at birth rather than before or after found to score higher in depression within this sample (see Table 4.10). For this sample, admission to the Neonatal Unit was not found to significantly impact DASS, MSSI or MKUS scores (Table 4.10).

Multiple Regression Analysis

In order to estimate the proportion of variance in maternal knowledge and understanding that can be accounted for by some predicting factors, a standard multiple regression analysis was performed. Prior to interpretation several assumptions were evaluated. The outcome variable MKUS was transformed to a log variable to minimize violation of normal distribution (Tabachnick & Fidell, 2007). Inspection of the normal P-P plot and scatterplot indicated that the assumptions of normality, linearity, and homoscedasticity were met. To avoid instability of the regression, variables with high correlations were not all included. Also, the required dichotomous ‘dummy’ variables were created for considered inclusion during development of the model.

The Multiple Linear Regression Model is illustrated in Table 4.11. With Anxiety as a dichotomous variable in combination with maternal factors, outside talks and relatives seen, accounted for 15% of the variability in MKUS, $R = .421$ and $R^2 = .177$. (See Table 4.12)

Table 4.12

Multiple Regression Model – Predictor variables for MKUS

Dependent variable – MKUS log variable

Predictors: (Constant) Relatives seen enough, someone to talk to, anxiety.

Dependent variable: MKUS score (log variable)

Model	Unstandardised		Standardised		
	Coefficients		Coefficients		
	B	Std. Error	Beta	t	Sig.
(Constant) 1	4.288	.017		249.829	.000
Anxiety	-.056	.024	-.228	-2.320	.023*
Outside talks	.066	.024	-.268	-2.749	.007**
Relatives seen	-.091	.044	-.202	-2.061	.042*

a. Dependent variable: MKU score (log variable).

The following multiple regression equation was calculated from the data:

$$Y = 4.288 + (-.056) (\text{Anxiety}) + (-.091) (\text{Outside talks}) + (-.066) (\text{Relatives seen}).$$

The standardized coefficients indicate a predicted change of 1 SD when there is anxiety, less outside talks and less relatives seen reducing the MKUS score by .228,

.202 and .268 of SD in MKUS respectively. The model overall generated an F statistic 6.252 and p value .001 (see Table 4.11).

Summary

In this section the response rates and characteristics of the participants was presented. Consistency of the instruments used in this study was outlined. Descriptive analysis was used to describe the characteristics of the mothers and children who participated in this study. To avoid violation of normal distribution, non-parametric bivariate analysis was performed with appropriate selection of Mann-Whitney U test or Kruskal-Wallis Test using maternal MKUS as the dependent variable to examine relationships between maternal and child factors. Parametric bivariate analysis was also performed with DASS and MSSSI as continuous outcome variables and one way analysis of variance and independent t tests were appropriately selected. Significant findings indicated maternal social support factors impacted maternal MKUS while mothers who scored higher in anxiety scored lower in MKUS. Mothers of children having more complex procedures were also found to have higher scores in depression.

The following section will discuss the relevance of these findings for nursing practice. This study's strengths and limitations will be identified and future directions will be considered with inference to the findings in this study.

DISCUSSION

Introduction

In this section the results of this study are summarised and interpreted in relation to the research questions and findings from the review of the literature. The validity of the MKUS instrument developed for the purpose of this research is interpreted and implication for its adaptation across the wider paediatric setting is considered. The impact of maternal and child characteristics, particularly maternal anxiety, maternal social support, and the complexity of the child's procedure as direct or mediating influences on maternal knowledge and understanding, are interpreted and related to the literature for relevance to nursing practice. The strengths and limitations of the research are critically examined and the implications for nursing practice are considered and future directions contemplated.

Overall, the aim to develop a measure for maternal knowledge and understanding of her child's condition and care at the time of surgery, and explore the impact of biopsychosocial influences were largely addressed. Findings demonstrated acceptable internal consistency and illustrated some relationships between maternal psychosocial factors and MKU. The results in this study support further development of the MKUS instrument. Interpretation of the findings in this research study will be discussed in the following pages with attention to the research questions.

Summary of research findings

Only ten per cent of the participants had not completed high school and only eight per cent spoke a language other than English at home. This is consistent with other quantitative studies where participants tend to be those who are better educated and more likely to find questionnaires less time consuming or difficult (Jackson & Mare, 2007). A reasonable level of social support was also reported indicating the likelihood of a more advantaged sample. A comparison between participants and those who chose not to participate showed a significant difference in level of advantage using the SEIFA to identify geographical location

Eight of the 14 statements in the MKUS instrument demonstrated acceptable internal consistency. As expected, reports of stress, anxiety, and depression were highly correlated among participating mothers. In bivariate analyses, financial strain was related to increased levels of maternal anxiety and the mothers of children who had the most complex cardiac procedures were more likely to report symptoms of

depression. An association was found between anxiety and mothers MKUS score, but not between stress or depression and MKUS score. In multiple regression analysis the combination of maternal anxiety, not seeing relatives as often as desired, and not having someone to talk to were associated with the mother having a lower MKUS score. The finding of a high correlation between stress, anxiety, and, depression scores suggests that maternal anxiety and depression could possibly mediate the relationship between the mother's sociodemographic and psychosocial characteristics, the seriousness of her child's situation, and her knowledge and understanding of her child's care.

Interpretation of findings

Maternal Knowledge and Understanding (MKUS) Instrument

The MKUS instrument sought to measure mothers understanding of their children's condition, and care at the time of cardiac surgery. However, results of the preliminary analysis using a 4-point Likert scale showed little variability. Thus most mothers had a clear understanding of their situation. These initial results were not anticipated because they did not meet the expectations of the researcher whose clinical practice showed that often many mothers did not understand information and were unsure about the care of their child needed. With confidence in both the anecdotal experience of less than optimal maternal functioning at this time, and research evidence for the importance of that functioning for children's health and developmental outcomes, it was decided to introduce a larger 10-point Likert scale. The intention here was to enhance sensitivity and distinguish between the mothers who were perhaps, less sure. The final results showed that there were no mothers in the sample who indicated that they had little knowledge and understanding of their child's care at all. However, there were a number of mothers who indicated that they were less than one hundred per cent confident about it. There are a number of possible explanations for these findings that will be discussed in the following paragraphs.

Firstly, it is possible that the items within the MKUS did not, in fact, measure anything meaningful. On the other hand, the questions were reviewed by colleagues locally and nationally working with families in the acute paediatric setting. Consensual agreement was reached that the questions were appropriately related to practice and the required maternal care. In the development phase, the questions

were reviewed for interpretation and readability by mothers from both hospital and community settings. Additionally the reasonable internal consistency of .78 demonstrated in the 8 items selected for final analysis, along with a significant association between MKUS and anxiety, provided some strength to the purpose of this instrument as a measure of MKUS.

Secondly, just as in clinical practice, these mothers may have been expressing their over-confidence in their understanding of the appropriate care required. The positive responses expressed as maternal confidence in their MKUS may not necessarily translate into effective behaviours by mothers. A lack of correspondence between attitudes and behaviours is well supported in health literature where disparities are found between what individuals approve of and what they actually do (Smith & Louis, 2009). Research exploring determining factors for this incongruence has found social norms and cultural goals to be particularly influential (Geschke, Mummendey, Kessler, & Funke, 2010). This implies that a high level of confidence should not be interpreted as the capacity to give optimal care. Then again, not all mothers expressed the same level of confidence. Lower levels of maternal confidence were associated with increased anxiety and less than desired social support in this sample.

Thirdly, the higher recorded levels of maternal confidence may have been a reflection of an educationally advantaged sample of mothers. The majority completed Year 12 and over a third held a university degree. Research findings support the positive relationship between education and having better health knowledge or health literacy (DeWalt & Hink, 2009). With the educational characteristics found in this sample, it was more likely that these mothers would have a reasonable idea about the questions included in the MKUS instrument. While no associations were found in this sample between maternal education status and levels of knowledge and understanding, administration of the MKUS instrument to a less advantaged sample of mothers is required to examine this further.

Fourthly, it is possible that the higher levels of maternal confidence in knowledge and understanding found in this more advantaged sample may reflect high levels of maternal confidence or self-efficacy. According to Racine et al. (2009), parents who are confident feel more able to cope, make decisions, and have more control managing their child's condition and care. Additionally, maternal self-efficacy has

been found to be a mediator between a mother's competence and sociodemographic influences and plays a crucial role in determining parental behaviour (Teti, 2008). Interestingly, this was supported in this sample with mothers with less confidence in their knowledge and understanding who also reported increased levels of anxiety and less social support.

Regardless of the MKUS as a measure of knowledge and understanding, maternal confidence, or both, the associations found between increased levels of anxiety reduced social support and lower MKUS scores warrants further exploration inclusive of a wider range of maternal characteristics. Also the relationships found between maternal anxiety, social support and MKUS scores in this sample of more advantaged mothers suggests that more associations would be likely in a sample inclusive of mothers from more disadvantaged circumstance. Findings in this study also support further development of the MKUS instrument as a measure of maternal knowledge and understanding and / or confidence to serve as an indicator for earlier nursing intervention. Further research examining relationships between mother's circumstances and their MKUS scores could provide support for adaptation of the MKUS instrument as an indicator for earlier nursing intervention that supports improved child health outcomes for the seriously ill child.

Relationships between financial strain and the child's diagnosis, anxiety and depression

It was clear that neither the characteristics of the mother nor the child were directly related to the mother's knowledge and understanding of her child's care. However, mothers participating in this study, who indicated they were struggling financially, experienced higher levels of anxiety than mothers who reported they could save money regularly. This finding supports the notion that money worries can be a considerable source of anxiety (Tong, Lowe, et al., 2008). Despite mothers in this sample being considered more advantaged than a wider sample, there was some indication of a relationship between the experience of stress and financial strain where the association was not quite statistically significant at $p = .05$.

Furthermore, the mothers of children who underwent more complex operations using the RACHS (Risk Adjustment for Congenital Heart Surgery) reported higher levels of depression than those whose children underwent less complex procedures. This is consistent with findings by Lawoko (2002), where mothers of children with complex

heart disease reported significantly higher incidences of depression and hopelessness than mothers of other children. This is a significant issue as the children who have surgery for more serious congenital abnormalities are already at a higher risk of having poor neurodevelopmental outcomes (Tabbutt, 2008; Wernovsky, 2006). These vulnerable children who, arguably, require optimal maternal care both pre and post-operatively, are less likely to receive it because their mothers are depressed and are not able to fully engage with them (Field, Diego, & Hernandez-Reif, 2009). Additionally, the presence of neurodevelopmental problems that may become apparent later can be an ongoing source of sadness for parents (Mussato, 2006). Interestingly, mothers who had their infant's heart disease diagnosed in the antenatal period reported lower levels of maternal support. The reasons for these findings are unclear. It could be considered that a mother who experiences the antenatal diagnosis of her unborn infant could possibly feel overwhelmed and isolated. Likewise a mother who does not have the support of a partner may feel less supported. However, further research is required to explore these areas to identify possible relationships.

Relationships between maternal anxiety, social support, and MKUS score.

In this sample, higher levels of reported maternal anxiety were associated with lower MKUS scores. This is consistent with the well accepted finding that mothers who are anxious are likely to have trouble thinking clearly (Patel, 2008; Weis & Lovejoy, 2002). The effects of stress, anxiety and depression on a mother's capacity to accurately hear, perceive and process information is well supported in research (Cerezo, Trenado, et al., 2006). Similarly, there is a body of research in the neurosciences that illustrate the negative effects of exposure to consistent stress on the body even prior to birth including alteration of the brain architecture with implications for cognition and emotional and physical responses later in life (McEwen & E., 2003; Szanton, Gill, & Allen, 2005). While stress and depression were not directly related to MKUS, the close associations between stress, anxiety and depression are consistently supported in health research (Blair et al., 2008; Lovibond, 1995; Schlesinger, Ober, McCarthy, Watson, & Seinen, 2007). It is quite feasible that stronger associations would be found in larger, more representative samples.

The importance of social support as a determinant for health is well documented with poorer health outcomes reported in families with less access to social and emotional support and socioeconomic advantage (Creedy et al., 2005; Reutter, Dennis, &

Wilson, 2001). Mothers in this study who were not living with someone in a relationship and whose babies were diagnosed before birth reported reduced social support. While this was not related directly to stress in this somewhat limited sample, research shows important associations between the effects of social support and level of stress on cognition and memory (Harrison, 1999; Ingram, Steidtmann, et al., 2008). Numerous studies have found that parents with seriously ill children consistently report the benefits of having someone to talk to about parenting their child both within and outside the family (Creedy, Ludlow, et al., 2005; Kerr et al., 2007; Tak & McCubbin, 2002). Findings in the current study showed that while mothers indicated a reasonable level of support around the home, those who reported little or no contact with relatives, and / or, did not have someone to talk to, achieved lower MKUS scores. While these findings are consistent with expectations, there is no published nursing research relating a mother's access to social and emotional support to knowledge and understanding about her child's condition and care.

The importance of maternal social support was emphasised further in multiple regression analysis in this sample which identified maternal anxiety, less contact with relatives, and not having someone to talk to, in combination, were predictors for a lower MKUS. While published findings have shown relationships between reduced access to support and stress and depression (Van Horn, DeMaso, et al., 2001) and the implications for reduced social support on child behavioural outcomes (Brosig, Mussatto, et al., 2007), there are no findings relating maternal social support to knowledge and understanding in the acute paediatric setting. The association between these predictors and MKUS score in this study invites further exploration of maternal sociodemographic characteristics and psychosocial factors and potential relationships to maternal knowledge and understanding in the hospital setting.

Maternal stress, anxiety, and depression as possible mediators, between family socio-demographic and psychosocial circumstance and MKU

Research evidence supports the notion that mothers who are anxious are also more likely to experience stress and/ or depression, particularly when their children are seriously ill (Davidson, 2009). Higher levels of maternal anxiety and reduced social support in this study were directly associated with lower MKUS scores. While the presence of financial strain was not significantly associated with MKUS, it was related to higher levels of maternal anxiety. Additionally, while there was no

significant impact on MKUS scores in mothers of children requiring more complex procedures, these mothers did report higher incidence of depression. Again, while not directly associated with MKUS score, mothers whose children were diagnosed before birth reported reduced social support. Strong associations between stress, anxiety and depression are consistently supported in health research (Blair, Granger, et al., 2008; Lovibond & Lovibond 1995; Schlesinger, Ober, et al., 2007). Therefore, the potential for stress, anxiety and depression to mediate among maternal and child sociodemographic and psychosocial characteristics and MKUS scores in this sample is likely. For example, the association found between maternal anxiety and financial strain could be related to MKU through anxiety. Likewise the relationship between the complexity of the child's surgical procedure and heightened maternal depression could influence MKU through depression. Further, examination in a more representative group could also see the lower levels of social support reported by mothers whose children were diagnosed before birth indirectly affect the MKU through stress. Additional nursing research highlighting these relationships could potentially identify opportunities for earlier nursing intervention to improve a mother's knowledge and understanding of her child's condition and appropriate care with positive long-term implications for health and development.

Strengths and limitations of the study

This study has a number of strengths. First, a review of the literature found there is no extant research that examines the relationship among maternal sociodemographic, psychosocial characteristics, knowledge and understanding in the acute paediatric setting. And yet, this is important because the mother is usually the primary care giver for her child and ultimately it is her care that will have the most influence on the child in the long term (Barnet, Liu, DeVoe, Alperovitz-Bichell, & Duggan, 2007; Carmichael et al., 2003). This study focused on mothers, their characteristics and sociodemographic circumstances and examined influences that can impact their knowledge and understanding of their children's condition and care.

Second, an instrument intended to measure a mother's knowledge of, and confidence in, giving appropriate care to her child who is experiencing cardiac surgery has been empirically tested. The MKUS instrument developed for the purpose of this study showed reasonable internal consistency. The correlation found between the 8 questions selected for final analysis showed consistent measurement of maternal

knowledge and understanding indicating reasonable reliability. Additionally, significant associations found among levels of maternal anxiety and social support and MKUS suggested some content and construct validity. These relationships supported associations that were anticipated prior to analysis.

The relationships found among maternal financial situation and anxiety and the complexity of a child's operation and maternal depression in this study, were consistent with published findings (Aber, Jones, et al., 2007; Tomasello, Manning, & Dulmus, 2010). Furthermore, these associations supported the possibility of mediating influences between maternal and child sociodemographic and psychosocial characteristics and mothers MKUS score.

Third, a well-tested set of questions and instruments designed to measure family socio-demographic and psychosocial characteristics has been used. The validated DASS and MSSSI instruments are widely used in health research as a measure of stress, anxiety and depression and level of social support reported by mothers. Both the DASS and MSSSI instruments were used to collect data in The Western Australian Pregnancy Cohort Study (Newnham et al., 2004) and Growing Up in Australia: The Longitudinal Study of Australian Children (LSAC) (Australian Institute of Family Studies, 2006). These instruments demonstrate acceptable reliability and construct validity (Lovibond, 1995; J. M. Pascoe, 1988). The significant relationships between mothers' heightened anxiety and lower level of social support and MKUS scores indicates some uniformity between the DASS, MSSSI and, MKUS instruments giving the MKUS instrument some merit.

The study also has two limitations. First, the response rate of 62% indicated that almost half of the mothers chose not to participate. In an effort to explain this, examination of maternal characteristics was limited to geographical location between participating and non-participating mothers using the SEIFA (Socioeconomic Index for Advantage and Disadvantage). Comparison between groups was statistically significant indicating that participants were more likely to be from advantaged areas suggesting an advantaged sample. Further research focusing on engaging and inclusion of mothers from a wider range of areas is required.

Second, the mothers recruited in this instance were educationally well advantaged and most reported reasonable levels of support around the home. While education is

recognised as a determinant of health (Li, Mattes, Stanley, McMurray, & Hertzman, 2009), no significant association between maternal education and knowledge and understanding was found in this sample as might have been expected. Findings suggested rather a question of associated anxiety and less maternal support. Despite advantaged maternal characteristics, a significant level of anxiety was reported suggesting prevalence among families with seriously ill children. This is consistent with the literature that endorses the impact of maternal anxiety on attachment, cognition and parental coping when children are seriously ill (Berant, Mikulincer, & Shaver, 2008; Power & Dell Orto, 2004). While the findings of the present exploratory study are interesting and valid, further research in a sample more representative of both disadvantaged and advantaged mothers is indicated.

Implications for nursing practice

Application of MKUS instrument to nursing practice

One of the principle aims of this study was to develop a measure for maternal knowledge and understanding of a child's optimal care at the time of cardiac surgery. While the MKUS instrument demonstrated reasonable internal consistency and it appears to have some content and construct validity, further research is required to develop its potential application across the wider paediatric setting. Adaptation of such an instrument could alert earlier opportunities for nursing intervention to facilitate parents in their understanding and care to their child with implications for child health and developmental outcomes across nursing practice in the paediatric hospital setting. Ultimately, application to practice could see nurses consistently ask the relevant questions as a natural part of nursing assessment similar to the practice of child health nurses who, for example use a community resource framework (Brooks-Gunn, 2003); or midwives who, refer to the Edinburgh Score as a part of their nursing care to mothers in the newborn period (Clifford, Day, Cox, & Werrett, 1999).

Nursing application of theoretical concepts

In this study, the focus on the mother's knowledge and understanding and developing confidence in the care she gives her child, draws attention to the importance of nursing application of the relevant theoretical concepts that support practice. These components are well supported within the Family Centred Care (FCC) framework. It is well understood that nurses who obtain the relevant physical and biopsychosocial

information about families in their care are more likely to initiate the most appropriate support for the family's needs (Brooks-Gunn, 2003).

It is understood that parents who feel judged or misunderstood are more likely to have difficulty developing a trusting relationship with nursing staff, and, are also less likely to engage in information sharing (Avis & Reardon, 2008). In contrast, there is evidence that the use of respectful, reflective dialogue and information sharing can assist families to clarify their concerns and identify their strengths, which can support ways of coping and renew some parental confidence (Edwards, Davies, & Edwards, 2009). This process has its roots in Friere's (1999) empowerment theory that promotes listening to understand and the use of a participatory dialogue as key elements. Reference to both family partnership and empowerment theory remains important because they sit well within the (FCC) nursing theoretical framework, where the child is cared for within the context of family (Haswell-Elkins et al., 2009).

Evidence for the benefit of paediatric nurses' giving attention to the sociodemographic and psychosocial characteristics of the families they care for is emphasised in this exploratory study. It is very likely that bioecological theory, attachment theory, the family and community resource conceptual framework, and the nurse-family partnership model are just as applicable in the clinical setting as they are in the community (Atkinson, Paglia, et al., 2000; Bidmead, Davis & Day, 2002 ; Bronfenbrenner & Ceci, 1994; Shonkoff, 2009). The extensive evaluation of interventions in community settings in the United States that are based on these concepts have been very positive with significant improvements seen in maternal and child health outcomes predominantly among young disadvantaged mothers (Dawley, Loch, et al., 2007; Olds, 2006). In Australia, similar intervention programmes have received extensive funding and have experienced significant growth in recent years particularly in the area of Indigenous health (Keatinge, Fowler, et al., 2007; Haswell-Elkins, Reilly, et al., 2009).

Implications for Nursing Research

While FCC that is applied in the paediatric context is predicated on the notion of the importance of mother-infant attachment, the development of the child and the psychosocial characteristics of families are seldom taken into account. Shields, (2010) recently questioned the relevance of FCC for paediatric nursing practice, but she is essentially talking about the worth of mothers “rooming in” with their children. And yet, FCC should be much more than this. Using the literature review produced for this thesis, the author and a colleague have questioned the application of FCC in its present form and have proposed that it be re-formulated to include the theory and associated practice discussed in the preceding paragraphs (Kendall & Tallon, 2011).

Conclusion

This study has introduced a measure for mothers' knowledge and understanding of their child's condition and care at the time of cardiac surgery. The instrument which shows reasonable internal consistency and some associations with maternal psychosocial characteristics supports the notion that nursing consideration for the child and family's physical, psychological, and social influences are very important. The findings in this study invite further nursing research that examines the impact of nursing care in hospital on child and family health outcomes.

There is a great deal nurses can do, if they understand the processes of early child development, family resources and the impact of stress, anxiety, and depression on the parents of children in hospital. By using bioecological theory and the resources conceptual framework nurses can appropriately identify these factors during routine assessment. Having identified parents who need additional support, nurses can use the nurse-family partnership model to guide their care. While there is no direct evidence showing that this form of care in the hospital setting is likely to improve health and developmental outcomes for children, there is a great deal of circumstantial evidence that suggests it will do so. The first task will be the re-formulation of FCC so that it appropriately reflects current theory and evidence-based knowledge in child development and family functioning. Following this a new type of FCC can be implemented in the paediatric setting and thoroughly evaluated. This programme of research and development will lead to the identification of the nurse's role, as distinct from other health professionals, in improving child health outcomes. By building relationships that support the development of parental knowledge and understanding nurses will enhance the capacity of parents to care for their seriously ill children optimally in the long-term.

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APPENDIXES

Appendix A: Invitation to participate

Dr D Forbes
Director Clinical Care Unit
Princess Margaret Hospital

Dear

I am writing to ask if you would be willing to be contacted by a researcher Mary Tallon who is undertaking a project 'The Effect of Anxiety and Psychosocial Factors on Mothers' Understanding of Their Child's Heart Disease and Care at the time of Cardiac Surgery' and wishes to recruit mothers of children attending this Hospital. From our records you would appear to be a potential subject for this study.

Benefits of this research include the validation of an instrument to measure maternal knowledge and understanding providing nurses in the paediatric a consistent grounding when providing education for parents. It is anticipated this work will give rise to innovative ways for nurses to evaluate mothers' knowledge and understanding of their child's heart disease and may have application to other areas of paediatric nursing. The people the researcher is looking for to help them with this study need to be: The child's mother or foster mother who is willing to complete a questionnaire, one a week before surgery.

If you do not wish to hear more about this study, or be contacted further, you need do nothing. If you are willing to be contacted by the researcher Mary Tallon, could you please complete the attached slip and return it in the envelope provided. The researcher will contact you shortly after to give you more information regarding the study. Should you wish to have further information about the study before making a decision as to whether or not you wish to be contacted, please telephone the researcher Mary Tallon - (08) 9340 8222 page 8982.

Whether or not you participate in this project, any future care you/your child receives at this Hospital will not be affected in any way.

This study has been approved by the Princess Margaret Hospitals Ethics Committee and the confidentiality of all participants is assured.

Thank you for considering this request.

Yours sincerely

**Director
Clinical Care Unit**

PLEASE TICK THE BOX, THEN SIGN, DATE AND RETURN THE SLIP IN THE ENVELOPE PROVIDED

I would like to be contacted by telephone about (Study title) so I can decide whether or not I/my child will participate.

Name: _____ (Child's Name): _____

Signature: _____ Date: _____

Appendix B: Information sheet

PARENT INFORMATION SHEET

Study Title: The Effect of Anxiety and Psychosocial Factors on Mothers' Understanding of the Care of Their Children Before and After Cardiac Surgery

Research Team; Mary Tallon, Dr. Garth Kendall, Dr. Paul Snider

You are invited to participate in a research project being conducted at The Children's Cardiac Centre, Princess Margaret Hospital in conjunction with Curtin University, Perth, WA.

This research has the approval of the Curtin University Human Ethics Committee and Princess Margaret Hospital Ethics Committee.

The aim of the study is to evaluate an instrument that effectively measures mothers' knowledge and understanding of their child's heart condition and care at the time of cardiac surgery and to evaluate the effect of anxiety, social support and sociodemographic factors on mothers' knowledge and understanding of their child's heart condition and care at the time of surgery.

As a participant you will be asked to complete a questionnaire one week before surgery. The questionnaire is about your child's health, you and your family, your feelings and social supports, and the care of your child. An instrument being used in this study has not yet been validated and will be tested for content, construct validity and internal consistency. It is anticipated that this questionnaire will take 30 minutes to complete.

The questionnaire will be identified only by a study number and information given will be confidential. The completed copies will be stored in a locked filing cabinet and accessed only by the researcher and her supervisors.

Participation in this study is completely voluntary. As a participant you are free to withdraw at any time without consequence or prejudice. Doing so will not affect in any way you and your child's access to health care and services.

The researcher will be available by phone call or appointment to answer or clarify any questions. Alternatively questions can be answered using an interview process with the researcher in an office setting within the Cardiology Department at Princess Margaret Hospital.

Please contact the Principal Supervisor: Dr. Garth Kendall on (08) 9266 2191 for any further information.

In the event of any questions or concerns of an ethical nature in relation to the intentions of this study you are welcome to contact the Secretary of the Human Research Ethics Committee, Curtin University on (08) 9226 2784.

Appendix C: Consent form

CONSENT FORM

Study Title; The Effect of Anxiety and Psychosocial Factors on Mothers' Understanding of the Care of Their Child Before and After Cardiac Surgery

Research Team; Mary Tallon, Dr. Garth Kendall, Dr. Paul Snider

I have been given clear written and verbal information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not in be in any way identifiable.

I understand I may withdraw from the study at any time without consequence, effect or access to routine health care.

I know that I can contact Dr. Jim Ramsay, Head of Cardiology Department on (08) 9340 8306 or the Research Supervisor: Dr. Garth Kendall on (08) 9266 2191 if I have questions or concerns.

I am aware that in the event of my having any complaints regarding this study, I can contact Dr Garth Kendall (08 9266 2191) on a **confidential basis**. My concerns will be drawn to the attention of the Ethics Committees who are monitoring this study. I am aware that Curtin University Human Ethics Committee and the Ethics Committee at Princess Margaret Hospital have given approval for this research to be conducted.

Participant Statement

I (Print full name), understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete two questionnaires at one week before surgery and following discharge from hospital after my child's heart operation.

I understand that my participation in this study is voluntary and I can withdraw at any time without affecting in any way my own and my child's access to health care and services.

Signature Participant

Signature Researcher

Date



Appendix D: Questionnaire

You, your child and cardiac surgery

Questionnaire

Cardiac Surgery

Curtin University of Technology
Princess Margaret Hospital for Children

The purpose of this questionnaire is to obtain information about: your understanding of your child's heart surgery, you and your family, your feelings and supports. Questions relate to your child who is undergoing heart surgery or yourself as parent / guardian.

Please take your time

If you are uncomfortable about a question or unsure of an answer, please leave it blank and the researcher, Mary Tallon, will call you to discuss it.

Remember ALL answers are confidential

Completion Instructions

Please use a black or blue pen to complete the questionnaire

Please print clearly where required

or

Please make marks that fill the circle

Please shade the circle completely



Please **do not** use crosses



Please **do not** use ticks



PART A: ABOUT YOUR CHILD WITH A HEART CONDITION

A1. What is your child's date of birth?daymonthyear
--	-------------------------------

	Male	Female
A2. What is your child's sex?	<input type="radio"/>	<input type="radio"/>

A3. What was your child's birth weight? lbs oz OR grams OR <input type="radio"/> don't know
--	--

A4. Was your child born late, on time or early?	
Late birth (42 weeks or more)	<input type="radio"/>
On time (37 – 41 weeks)	<input type="radio"/>
Somewhat early (33 – 36 weeks)	<input type="radio"/>
Very early (32 weeks or less)	<input type="radio"/>

	Yes	No	Don't know
A5. Did your child have to go into a Neonatal Intensive Care Unit or Special Care Nursery after he/she was born?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A6. Was your child a single birth, or a twin, triplet or more?	
Single birth	<input type="radio"/>
Twin	<input type="radio"/>
Triplet	<input type="radio"/>
More than a triplet	<input type="radio"/>

A7. When was your child's heart condition diagnosed?	
Before birth	<input type="radio"/>
As a new born baby	<input type="radio"/>
In the first year of life	<input type="radio"/>
Later	<input type="radio"/>

A8. Does your child have any of these ongoing health problems? (Please mark all that apply)

Hearing problems	<input type="radio"/>	Eyes or seeing properly	<input type="radio"/>
Attention Deficit Disorder (ADD or ADHD)	<input type="radio"/>	Eczema	<input type="radio"/>
Diarrhoea or colitis	<input type="radio"/>	Frequent headaches	<input type="radio"/>
Ear infections	<input type="radio"/>	Other infections	<input type="radio"/>
Food or digestive allergies	<input type="radio"/>	Other illnesses	<input type="radio"/>
Other physical disabilities	<input type="radio"/>		

A9. If your child has any ongoing health problem, please describe the condition and medical treatment. If your child does not have an ongoing health problem, please go to A10.

.....

.....

.....

.....

	Yes	No	Don't know
A10. Have you ever been told that your child requires antibiotic protection in the event of dental or general surgery?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART B: ABOUT YOU AND YOUR FAMILY

B1. What is your date of birth?

	Yes	No
B2. Do you mostly speak English at home?	<input type="radio"/>	<input type="radio"/>
If No, what language to you mostly speak?		

B3. Which of these categories best describes your highest schooling / education?

Didn't complete High School	<input type="radio"/>
Completed High School (Leaving Certificate)	<input type="radio"/>
Completed High School (TEE or equivalent)	<input type="radio"/>
Apprenticeship/TAFE diploma	<input type="radio"/>
University Degree	<input type="radio"/>
Other, not included above (please specify).....	

	Yes	No
B4. Do you currently have a full-time or part-time job of any kind (excluding home duties)?	<input type="radio"/>	<input type="radio"/> Go to B6

B5. Describe your current main job. (Please give the title of your job and description of your work)

Job (Occupation, Profession) -

Description -

B6. What is your current relationship status?

Single and not living with someone in a relationship	<input type="radio"/>
Living with someone in a relationship	<input type="radio"/>
Married (registered marriage)	<input type="radio"/>
Separated or divorced (either registered or de facto relationship)	<input type="radio"/>
Widowed (either registered or de facto relationship)	<input type="radio"/>

B7. How many adults and children live in your home? (Please include yourself. Children less than one year of age: age = months)

First name	Age years	Age months	Sex M/F	Relationship to you
e.g. Diane	31		F	Mother
e.g. Brian	34		M	Partner
e.g. Karyn	4		F	Daughter
e.g. Cameron		11	M	Son
.....
.....
.....
.....
.....
.....
.....
.....

The following question is about your financial situation. All of the information collected in this questionnaire is strictly confidential.

B8. Which words best describe your family's money situation? (Please mark one answer only)

- We are spending more money than we get.
- We have just enough money to get us through to the next pay day.
- There's some money left over each week, but we just spend it.
- We can save a bit every now and again.
- We can save a lot.

PART C: ABOUT YOUR FEELINGS – RELATIONSHIPS – SOCIAL SUPPORT

C1. Please read each statement and mark a circle 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any one statement.

Did not apply to me at all.	0			
Applied to me to some degree, or some of the time.		1		
Applied to me a considerable degree, or a good part of the time.			2	
Applied to me very much, or most of the time.				3
	0	1	2	3
I found myself getting upset by quite trivial things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I just couldn't seem to get going.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had a feeling of faintness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced breathing difficulties (eg. excessively rapid breathing, in the absence of physical exertion).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt sad and depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it hard to calm down after something else.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I perspired noticeably (eg. hands sweaty) in the absence of high temperatures or physical exertion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting impatient when I was delayed in any way (eg. lifts, traffic lights, being kept waiting).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself in situations which made me so anxious I was most relieved when they ended.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tend to over-react to situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting upset rather easily.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feelings at all.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found that I was very irritable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness in my mouth.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had lost interest in just about everything.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could see nothing in the future to be hopeful about.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of the action of my heart in the absence of physical exertion (eg. heart rate increase, missing a beat).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt scared without any good reason.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that life wasn't worthwhile.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did not apply to me at all.	0			
Applied to me to some degree, or some of the time.		1		
Applied to me a considerable degree, or a good part of the time.			2	
Applied to me very much, or most of the time.				3
	0	1	2	3
I couldn't seem to get enough enjoyment out of the things I did.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had a feeling of shakiness (eg. legs going to give way).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do something.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it hard to wind down.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was intolerant of anything that kept me from getting on with what I was doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had difficulty in swallowing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feared that I could be "thrown" by some trivial but unfamiliar task.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was pretty worthless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to become enthusiastic about anything.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was in a state of nervous tension.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was close to panic.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't much as a person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to relax.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt terrified.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (e.g. in the hands).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting agitated.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that life was meaningless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to tolerate interruptions to what I was doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C2. These questions are about how much help you get in the care of your home and child(ren). (Please mark the most correct answers)

At home,	No-one	You only	You and/or someone else
Who gets the meals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who does the grocery shopping?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who disciplines the children?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who fixes things around the house?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who does the inside cleaning?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who works outside around the house?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who pays the bills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who takes care of car problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who takes your child to the doctor when he/she is sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who sees to it that the children go to bed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C3. How many relatives do you see once a week or more?

C4. Do you see your relatives ...

Often enough?	<input type="radio"/>
Too often?	<input type="radio"/>
Not often enough?	<input type="radio"/>
Other, please explain	<input type="radio"/>

C5. How many people can you count on in times of need?

C6. How many people in your neighbourhood do you think would be able to help you in taking care of your child(ren) for a couple of hours if needed?

C7. How happy are you in the way your partner lets you know what they feel or think?

Happy	<input type="radio"/>
Not happy	<input type="radio"/>
Other, please explain	<input type="radio"/>
I don't have a partner	<input type="radio"/>

C8. Is there anyone (not including your partner) over 14 years old with whom you have regular talks? This can be someone inside or outside the home.

Yes

No

C9. Who do you talk to most?

C10. How happy are you with your talks with this person?

Happy

Not happy

Other, please explain

PART D: ABOUT YOUR CHILD’S HEART CONDITION AND PLAN FOR SURGERY

I can describe the long term benefits the surgery will bring my child.	< 1 2 3 4 5 6 7 8 9 10 >
I am aware of the risks associated with the surgery planned for my child.	< 1 2 3 4 5 6 7 8 9 10 >
Being kept informed of progress in the operation room at intervals during the operation will make no difference to me.	< 1 2 3 4 5 6 7 8 9 10 >
My child will be in the Intensive Care Unit (ICU) immediately following surgery and for a period of 1-3 days.	< 1 2 3 4 5 6 7 8 9 10 >
My child will require the support of the ventilator (breathing tube) for a period of time after surgery.	< 1 2 3 4 5 6 7 8 9 10 >
My child will be deeply sedated and will not respond to my cues immediately following the operation.	< 1 2 3 4 5 6 7 8 9 10 >
My presence or absence in the ICU will make no difference to my child or myself during this time.	< 1 2 3 4 5 6 7 8 9 10 >
My child will be allowed to recover at his/her own pace and have the breathing tube and drains removed accordingly.	< 1 2 3 4 5 6 7 8 9 10 >
It is important my child’s surgical dressing is kept dry and in place for period of 10 days following surgery.	< 1 2 3 4 5 6 7 8 9 10 >
As my child recovers on the Ward administering regular pain relief will be necessary.	< 1 2 3 4 5 6 7 8 9 10 >
Weight loss following surgery is anticipated.	< 1 2 3 4 5 6 7 8 9 10 >
Sudden weight gain is of no concern.	< 1 2 3 4 5 6 7 8 9 10 >
I can explain to family and friends the signs in my child that will bring me to seek medical attention.	< 1 2 3 4 5 6 7 8 9 10 >
I know who to call in the event of any concern that may present itself prior to my child’s next appointment.	< 1 2 3 4 5 6 7 8 9 10 >
I know when my child’s next appointment is.	< 1 2 3 4 5 6 7 8 9 10 >

**Thank you very much, we appreciate the time you have spent
completing this questionnaire**

**Please forward your completed questionnaire in the attached
stamped addressed envelope**

