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# The Lived Experiences of Families Who Have Attended a Cardiogenetics Clinic

## Abstract

This study explored the lived experiences of the family members who have participated in a Cardiogenetics Clinic at The Children's Hospital at Montefiore, which utilizes an interprofessional approach to care. A qualitative phenomenological approach was used to explore the lived experience of the families. Families that are referred to the clinic have suffered the loss of a family member to sudden cardiac death (SCD). This interprofessional model of care offers information regarding SCD, a genetic profile to determine risk for SCD, an integrative collaborative approach to care as well as nursing, medical interventions, psychological support, and counseling. The theory of health as expanding consciousness and science of unitary human beings theory were used to gain insight into how the interprofessional care provided by the Cardiogenetics Clinics influenced SCD families' understanding of their lived experiences. Insights gained may allow the interprofessional team to improve the quality of care being provided to SCD family members as well as establish a new model of care for genetic testing and disease management.

## Document Type

Dissertation

## Degree Name

Doctor of Education (EdD)

## Department

Executive Leadership

## First Supervisor

Mary Alice Donius

## Second Supervisor

Dorothy Larkin

## Subject Categories

Education

12-1-2011

# The Lived Experiences of Families Who Have Attended a Cardiogenetics Clinic

Esma D. Paljevic  
*St. John Fisher College*

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The Lived Experiences of Families  
Who Have Attended a Cardiogenetics Clinic

By

Esma D. Paljevic

Submitted in partial fulfillment  
of the requirements for the degree

Ed.D. in Executive Leadership

Supervised by

Mary Alice Donius, Ed.D., RN

Committee Member

Dorothy Larkin, Ph.D., RN

Ralph C. Wilson, Jr. School of Education  
St. John Fisher College

December 2011

## **Dedication**

There are many individuals I would like to thank for their support throughout this journey, first and foremost, Dr. Mary Alice Donius and Dr. Dorothy Larkin. I would not have reached this milestone without your support and guidance. You have helped me move beyond my boundaries, successfully. Thank you for being my committee, I was incredibly lucky. I would also like to thank Colleen Bimbo, who is my lifeline to my committee members and is always so kind and compassionate.

I am very grateful for support from my family, especially my children, Sophia and David. Their constant encouragement and love was always the light at the end of the tunnel. To my husband, Paul, who put up with all of the stressful times throughout the years. To my mom, my dad, and my brother for their love and support.

### **Biographical Sketch**

Esma Paljevic is currently a Pediatric Nurse Practitioner at The Children's Hospital at Montefiore Medical Center. Mrs. Paljevic attended Mercy College from 1996 to 1998 and graduated magna cum laude with a Bachelor of Science degree in 1998. She attended New York University from 2000 to 2003 and graduated with a Master's of Arts degree in 2003. She came to St. John Fisher College in the summer of 2008 and began doctoral studies in the Ed.D. Program in Executive Leadership. Mrs. Paljevic pursued her research in the lived experiences of cardiogenetics families under the direction of Dr. Mary Alice Donius and Dr. Dorothy Larkin and received the Ed.D. degree in 2011.

## **Acknowledgements**

I want to take this opportunity to express my sincerest thank you to the faculty in the School of Education's Executive Leadership Program at St. John Fisher College, the College of New Rochelle, and The Children's Hospital at Montefiore Medical Center for supporting this endeavor.

Specifically, I extend my warmest thank you to my academic advisor, Dr. Ronald Valenti at the College of New Rochelle, for his continuous support. I would also like to extend my gratitude to the interprofessional team of the Cardiogenetics Center at the Children's Hospital at Montefiore. I would specifically like to thank Dr. Christine Walsh for being that compassionate ear to listen to "my process."

Furthermore, I would like to thank Dr. Kathleen Kenney-Riley, Dr. Daphne Hsu (Chief of Pediatric Cardiology at The Children's Hospital at Montefiore), Dr. Gregory Gates, and Cathy Cahill, MSN for providing me academic and professional support, which I greatly appreciate.

## **Abstract**

This study explored the lived experiences of the family members who have participated in a Cardiogenetics Clinic at The Children's Hospital at Montefiore, which utilizes an interprofessional approach to care. A qualitative phenomenological approach was used to explore the lived experience of the families. Families that are referred to the clinic have suffered the loss of a family member to sudden cardiac death (SCD). This interprofessional model of care offers information regarding SCD, a genetic profile to determine risk for SCD, an integrative collaborative approach to care as well as nursing, medical interventions, psychological support, and counseling. The theory of health as expanding consciousness and science of unitary human beings theory were used to gain insight into how the interprofessional care provided by the Cardiogenetics Clinics influenced SCD families' understanding of their lived experiences. Insights gained may allow the interprofessional team to improve the quality of care being provided to SCD family members as well as establish a new model of care for genetic testing and disease management.



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## **Chapter 1: Introduction**

### **Introduction to the Study**

A qualitative study was conducted to explore the lived experiences of families that have experienced a sudden cardiac death and attended an interprofessional clinic for follow-up care. The first chapter presents the background of the study, specifies the problem of the study, describes the significance of the proposed study, and presents an overview of the methodology to be used. The chapter concludes with definitions of special terms that were used in the study.

### **Problem Statement**

Each year in the United States approximately 4,000 people under the age of 35 die suddenly due to a previously undiagnosed and unanticipated disturbance in heart rhythm (American Heart Association, 2009). This phenomenon, known as sudden cardiac death (SCD), is a condition whereby a person suffers from sudden collapse of the heart that most often results in death within one hour of the onset of symptoms in a previously healthy individual (Sovari, Kocheril, & Baas, 2010). For families, this loss may be unexpected and devastating.

In families where one family member has suffered SCD the chance of this occurring in other family members increases (Priori & Napolitano, 2007). The reality of SCD may be intensified for the family members when they are told that in at least one-third of these cases an inherited genetic disorder in cardiac channel proteins may have caused the unexpected death (Hendriks, Hendriks, Birnie, Grosfeld, Wilde, Van den

Bout, Smets, Van Tintelen, Ten Kroode, & Van Langen, 2008). Compounding the family's loss is the fear they may experience as they begin to realize the possibility that they or their immediate family members may suffer a similar fate.

Because of advances in medicine the genetic etiology of cardiac channelopathies is better understood. Commercially available testing may be able to determine individual risk assessment. Once DNA testing is performed and at-risk individuals are identified, the development of medical interventions such as implantable cardiac defibrillators as well as personalized life-saving treatment for those at risk can be offered. Some examples of personalized treatments in gene-specific cardiac channelopathies are the use of medications such as beta-blockers and avoidance of competitive sports. If left untreated, as many as 13% of the at-risk individuals may succumb to SCD before the age of 30 (Modell & Lehmann, 2006).

As families struggle to cope with their loss due to SCD, they are often seeking answers to what caused their loved one to die suddenly and whether they or others in their family are at risk for suffering the same fate. In the past, these families experienced fragmented care because it was necessary to seek care from many different health care providers, such as registered nurses, advanced practice nurses, cardiologists, geneticists, genetic counselors, and psychologists or psychiatrists (Hendriks, Hendriks, Birnie, Grosfeld, Wilde, Van den Bout, & VanLangen, 2008). In 1996, in the Netherlands, the first interprofessional clinic was developed (Hendriks et al., 2008). This new model of care delivery offered families who had experienced SCD clinical information and medical evaluations as well as psychological support and counseling. Through DNA testing the clinic identified those family members at risk for SCD. The goal of the clinic

was to educate all family members regarding diagnosis, treatment options, and potential benefits of treatment, as well as addressing their physical and psychological needs (Hendriks et al., 2008).

The Cardiogenetics Clinics are a new model of care designed to provide families with comprehensive, coordinated care as well as the medical and psychological support they need. The goal of these clinics is to identify those family members at risk for SCD, treat those who are identified with the genetic predisposition for SCD, offer medical and psychological support to these families to decrease their level of uncertainty about the future, and improve their quality of life. This goal is reflected in the mission statement presented in The Strategic Plan for the decade 2009-2019 that was developed for Montefiore Advancing Health and Enriching Lives mission statement (Appendix A).

The Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing, at the Institute of Medicine (CIOM), issued recommendations entitled: The Future of Nursing: Leading Change, Advancing Health (2011). This document provided evidence-based data and recommendations for encouraging nurses to take an active role in health care and leadership. One of the major recommendations is to provide seamless coordinated care within an interprofessional setting. The advanced practice nurse (APN) is well positioned to help meet the evolving health care needs.

The APN has a vital role in achieving patient-centered care, strengthening interprofessional services, providing community outreach programs, and providing seamless, coordinated care (CIOM, 2011). APNs have an opportunity to rise to the challenge of providing leadership in rapidly changing healthcare settings and in an evolving health care system. The APN in a Cardiogenetics Clinic is responsible for

contacting the families and providing ongoing communication, education, and support throughout the process (Appendix B). A primary role of the APN in a Cardiogenetics Clinic is to help these family members understand their clinical diagnosis, accept their risk level, support healthy decision-making, and promote their health and well-being.

The Children's Hospital at Montefiore Medical Center (CHAM) in the Bronx, New York, developed one of the first interprofessional Cardiogenetics Clinics (hereafter referred to as the Cardiogenetics Clinic) in the metropolitan area to help care for families who have experienced SCD. The Cardiogenetics Clinic offers an integrated and comprehensive interprofessional approach to care, which is part of the strategic plan of Montefiore (Appendix A). In the Cardiogenetics Clinic, families who have experienced SCD are offered state-of-the-art testing and intervention through a collaborative effort of various specialists including adult and pediatric cardiologists, geneticists, genetic counselors, social workers, psychologists, and an APN. Prior to the development of this interdisciplinary model, many families experienced fragmented care for diagnosis, evaluation, and treatment of SCD. This comprehensive interprofessional approach seeks to provide medical, nursing, genetic, and psychosocial care for these families in an integrative approach.

This new model of interprofessional care in the Cardiogenetics Clinic is intended to identify the risk in those family members at risk for SCD, decrease the stress of each family member, and offer a supportive environment as they deal with their risk of SCD, as well as their anxiety and perceived suffering (Appendix A). The comprehensive role of the APN (Appendix B) is integral to the structure and function of the clinic. The APN is the main connection between the families and each of the professionals and helps to



facilitate the families moving through the process of attending the Cardiogenetics Clinic. The APN is the first point of contact for the families. The bond between the APN and families begins at the initial phone call to review the processes of the clinic. As these families share feelings, hopes, and fears, the APN helps each family member move through the evaluation and testing process and supports them as they await their results and consider their treatment options.

The APN is integral in the design and implementation of the Cardiogenetics Clinic at CHAM. The holistic perspective of the APN provides the collaborative and integrated framework for the delivery of care in this new model. The role of the APN within this interprofessional model of care is that of a holistic care provider, facilitating collaboration between the multiple disciplines participating in the clinic and assuring open communication between the professionals and families in order to allow for optimal care for patients. In addition to working with families, the APN oversees the day-to-day operations and keeps a database of all the families' demographic information and test results.

The initial case review is performed by the APN prior to acceptance to the clinic. The APN presents cases that are referred to the Cardiogenetics Clinic to the interprofessional team to determine if the family will be seen by this Clinic team. The APN provides all necessary medical information and test results to each professional to facilitate the evaluation process. As additional testing is ordered and completed the APN disseminates all results to appropriate personnel. Once everyone has reviewed the case, the APN organizes and schedules the case reviews for a collaborative meeting to allow

for input from all professionals and to assure that a holistic approach to each patient/family is achieved.

Currently, the Cardiogenetics Clinic is offered twice a month at CHAM. Families who have had a family member suffer SCD are referred for evaluation and treatment. Prior to their initial visit for evaluation at the clinic, the APN contacts the families by phone to review the historical events surrounding the family member's death, review autopsy results, and assure that all required information for a comprehensive evaluation is obtained. The APN schedules the families for an initial visit with multiple specialists who will evaluate them at the initial and subsequent visits. The first visit entails a comprehensive family history, including medical, social, and demographic information. Each family member is evaluated and receives a physical exam, appropriate testing, including electrocardiogram (ECG), echocardiogram, and stress testing, as well as laboratory tests that include basic metabolic evaluation and DNA testing.

The families of the Cardiogenetics Clinic meet with the APN, adult and pediatric cardiologists, geneticist, genetic counselor, social worker, and a psychologist as a group during the initial evaluation process. The APN is present throughout the visit and is responsible for explaining the genetic testing and obtaining consent from all family members for the DNA testing. The APN also answers questions during this group meeting to facilitate the dialogue in a mutual process. Once the initial visit is completed, the families are scheduled for a subsequent visit. The APN is identified as the primary liaison for the families. They are given the APN's contact information for any additional questions or concerns the family may have.

At the follow-up visit, the family members receive the results of their individual risk for SCD, as well as possible interventions and/or treatments that may be recommended. During this visit, the results of the testing are given to the individuals in an interprofessional meeting with the family along with the cardiologist, geneticist, psychiatrist, social worker, and the APN. The family members are given time to ask any questions or to ask for clarification that may be needed prior to discussing treatment options.

Those family members who have tested positive for the gene for SCD are provided with treatment options including, medication, surgical insertion of an internal defibrillator (ICD), cardiopulmonary resuscitation (CPR) instruction, and activity restriction. Patients are given prescriptions for recommended medications and scheduled for an appointment to place a 24-hour cardiac monitor on the patient. Individuals who have elected to have an ICD inserted are scheduled for surgical procedure. The APN is present for all communication and coordinates all appointments and procedures. In addition, the APN continues to be the main point of contact for the families, including facilitating ongoing care and offering support. Patients with the genetic predisposition for SCD continue to be followed in the Cardiogenetics Clinic on an ongoing basis following interventions and treatments. The APN helps facilitate all future care for these families and offers ongoing presence in the moment, support, information, and education as needed.

Family members whose DNA results are undetermined for risk of SCD are offered the opportunity to participate in an investigational study. These patients are told that further investigative research is ongoing in the clinic to determine whether they are,

in fact, truly at risk for SCD or not. They are told this testing may take up to one year before results will be available to them. These patients are not prescribed any medication or offered any intervention because of the undetermined risk. These patients are given the contact information for the APN and told they will be contacted when the investigational testing is completed. However, the patients are offered counseling at the time of this discussion and, if needed, are given ongoing counseling while they await their final results. The APN serves as an ongoing contact for these patients regarding any questions, concerns, need for support, dialogue, or any additional information they may seek.

Patients who are negative for the gene for SCD are discharged from the clinic after they receive all of their test results and all their questions have been answered. Once again, the APN is present during this visit and serves as a liaison to the families and their primary care providers for any future questions they may have.

The interaction between the APN and the families is an integral part of the clinic. The APN is the initial contact for the families in the setting. The APN helps facilitate the organizational process for the families by scheduling testing and follow-up appointments. Additionally, the APN listens and provides support for communication with these families as they move through this process of discovering their risk for SCD and possible treatment options. This APN-centered interprofessional model of care is an attempt to provide holistic comprehensive care.

Nursing's role in this evolution of patterns of the human-environment process is being present with families as they process the information and learn a new pattern of interaction within their lives. The nurse enters this process with an open mind, striving to suspend preconceived ideas. The nurse allows the process to occur and offers the families

an open and nonjudgmental environment as they move through to a new level of patterning. The APN in the Cardiogenetics Clinic listens to the families, provides information and results, offers emotional support, and connects them to support services they may need. This model of care for nursing is intended to decrease the stress of each family member and offer a supportive environment as they deal with the reality of their risk of SCD, as well as reduce their anxiety and suffering. Gaining an understanding of the families' experiences throughout their interactions within this setting will allow advanced practices to improve upon this role of the nurse and enhance their ability to help these families process their experiences.

For families presenting to the Cardiogenetics Clinic, the APN initiates a partnership with the family members who are experiencing disruption and uncertainty in their lives. "A reflective dialogue centering on the meaningfulness" (Newman, 2008, p. 9) of these families' patterns and relationships is maintained with the APN during the period of perceived uncertainty. In order to explore and recognize the possibility of change in patterning, providing a holistic approach by the APN may help in the process. The APN is integral in the process by engaging in the evolving process of the family members understanding and recognizing health as the pattern of the whole so the families may see disease not as a separate entity but as a manifestation of the evolving pattern of person-environment interaction (Newman, 2008).

### **Theoretical Rationale**

This study used Newman's (1994, 2008) theoretical framework of health as expanding consciousness (HEC) to understand the lived experiences of families who participate in the Cardiogenetics Clinic at CHAM. Newman's theory was developed to

address the situation of the person for whom the concept of health must incorporate the reality that illness may be a dimension of their health. Newman recognized that for some the ability to live without disease or illness is not possible, yet these same people may be able to achieve an experience of health within the concepts of her theory. The APN partners with the families in the Cardiogenetics Clinic to grow and expand their consciousness to find greater meaning in life and gain a new appreciation of connectedness to their environment. One of the key concepts of Newman's HEC theory is the concept of pattern. Newman described pattern as revealing "the client's story of relationships with others and in her or his physiological interactions within and with the environment" (Newman, 2008, p. 99).

Newman's (1994) view of health and disease emerged from Rogerian science-based nursing theories and are manifested in the pattern of the human being. The purpose of nursing "is to promote the health and well-being for all persons wherever they are" (Rogers, 1992, p. 28). An exploration into not only a nursing theory but also a framework for nursing practice is Rogers' science of unitary human beings (SUHB). Rogers provided a framework for nursing study and research. She identified the traditional nursing framework as reductionistic, mechanistic, and analytic. Her unitary framework allows for an alternative worldview that has challenged many traditional ideas about fragmented health care.

Rogers' (1970) conceptual framework has five basic assumptions, which are wholeness, openness, unidirectionality, pattern and organization, and sentience and thought. Rogers' (1970) framework is summarized in the following ways. The human being is considered a unified whole which is different from the sum of its parts. The

person and the environment are continuously exchanging matter and energy with each other. The life process exists along an irreversible space-time continuum. Pattern and organization are used to identify individuals and mirror their wholeness. Human beings are the only organisms able to think abstractly, have language, sensation, and emotion. Rogers' theory further described the elements of nursing's metaparadigm in the following ways (1992). A person is an open system, different from the sum of its parts. The environment is an energy field including everything that is not the person. Health is viewed in terms of choosing actions that lead to the fulfillment of a person's potential, and nursing tries to direct the interaction of the person and the environment in order to maximize health potential.

The APN in Cardiogenetics Clinic creates an environment that fosters the health and well-being of all families that come for care. The APN's holistic approach to the family is guided by Rogers' (1992) conceptual framework. The family members call, anxious to connect with an individual who cannot only help them but, more importantly, understand their emotional pain. The APN tries to address these emotional needs as he/she addresses the families in a holistic manner noting individual patterns of the family members.

Rogers (1992) made note of changes in the terminology she used across time. She differentiates pattern from patterning, stating: "Pattern is an abstraction that reveals itself through its manifestations" (p. 31). She stated that manifestations of patterning "are continuously innovative while the evolution of life and non-life is a dynamic, irreducible, non-linear process" (p. 31). With regard to the importance of pattern and patterning in the application of Rogers' conceptual system in contemporary nursing practice, that

patterning in the life of a patient or family is an observable emergent of the person-environment process and is especially relevant to the use of Rogers' work in the practice of nursing. The concept of Rogers' description of patterning is useful in nursing practice, as nurses encounter people in the patterning of their lives and facilitate in mutual process and patterning in promoting health.

Newman's (1994) theory of HEC supports Rogers' (1992) perspective that each person has a unique pattern. HEC theory has been derived from Rogers' SUHB theory and includes genetic patterns as well as movement, diversity, rhythm, energy exchange, and transformation. Newman described nurses as becoming therapeutic partners with patients who are searching for pattern and meaning toward the expansion of consciousness and health as an evolving process of developing self-awareness. Within Newman's theory (1994) "characteristics of patterning include movement, diversity, and rhythm. The pattern is in constant movement or change; the parts are diverse and are changing in relation to each other; and movement is rhythmic." (p. 72)

The families that present to the Cardiogenetics Clinic seek medical, genetic, and psychosocial care. Newman's (1994) theory of HEC, as it relates to this study, strives to identify the unique pattern these family members embody. The APN had a meaningful role of participating in the therapeutic partnership with these families during a time of suffering. In fact, the nurse researcher, the APN in this clinic, played an integral role during the time of the interview process. The researcher established trust and mutuality as she participated in the discussion of the individuals' most meaningful lived experiences during a time of suffering a loss. The APN encouraged dialogue and reflection in a nonjudgmental environment.



The integration of theory, practice, and research is known as nursing praxis according to Newman (2008). As Newman's (1994) HEC theory has explored, dialogue and reflection provide an opportunity for insight, which can lead to choice, change, or transformation. The practice and research of HEC theory has proposed that suffering may be viewed as an opportunity for change. Newman has often described consciousness as being the evolving pattern of the human environmental system in flux.

During the time that families attend the Cardiogenetics Clinic, suffering may create chaos for the individual members. The APN helps them by facilitating discussion of their lived experiences in an environment that allows them the freedom to explore and process their feelings in order to promote optimal health potential. Newman's (1994) theory of HEC described suffering as possibly being a time of growth and understanding. It is during this most difficult time that there is possibility of exploring the connections between meaning and pattern that can lead to further understanding, and, then, transformation may occur. The goal of this study was to explore the lived experiences of these family members and to generate knowledge of how interprofessional care as provided by the Cardiogenetics Clinic influenced SCD families' understanding of their lived experiences. Newman's (1994) HEC theory was used as a foundation for facilitation of the family interviews. Guided by this theory, the nurse researcher entered into a partnership with the families at a time when they were experiencing disruption and uncertainty. The APN interviewed these families, seeking to create a reflective dialogue centering on the meaningfulness of the family's pattern of relationships and experiences as they explored their experiences participating in the Cardiogenetics Clinic.

## **Study Significance**

In families where one family member has suffered SCD, the chance of this occurring in other family members increases (Farnsworth, Fosyth, Haglund, & Ackerman, 2005). Typically, relatives of young sudden death victims are referred to cardiologists for a history and physical to evaluate any identifiable risk factors he/she may have. Recently, with the advent of new DNA testing, health care providers have the opportunity to identify those family members with the genetic predisposition for SCD as well to identify those who are not at risk. Prior to the availability of genetic testing, family members were referred to multiple specialists, including cardiologists, geneticists, social workers, and psychologists, to identify whether they were at risk for SCD and to deal with the emotions of losing a loved family member. Now a more comprehensive approach to these families has been developed at some medical institutions. The Cardiogenetics Clinic provides a comprehensive approach where family members are seen and cared for by many interprofessionals at one visit. Families are seen as a group by multiple specialists offering a more comprehensive model of care. Health care providers in the Cardiogenetics Clinic include: cardiologists, geneticists, an advanced practice nurse, social workers, and psychologists.

The APN's role is to facilitate the processes of the Cardiogenetics Clinic for the family members and to be with them as they incorporate the risk of SCD into their daily lives and evolve a new pattern of living. Newman (1994) described patterns as a theoretical concept of identifying the wholeness of an individual. "Families' perceptions, feelings and understandings as they live day to day, in mutual process with their environments, are integral with their life patterns." (Falkenstern, Gueldner, & Newman,

2009, p. 267). Within the framework of HEC, the APN engages with the family to create a mutual-process partnership, which is integral to exploring the lived experience.

Through the nurse researcher's explorations of these families' experiences, nursing may better understand and help facilitate their evolving life patterns. This study explored themes that may help identify the impact on how a family's experiences are changed by participating in this specialized clinic. To date, there have been several studies (Anderson, Oyen, Bjorvatn, & Gjengedal, 2008; Farnsworth et al., 2005; Hendriks et al., 2008; Ingles, Lind, Phongsavan, & Semsarian, 2008) assessing the psychological impact of this integrated and comprehensive model of care. However, there have been no studies that have explored the lived experiences of the families participating in a Cardiogenetics Clinic.

As clinical research in this field has provided the ability to better identify those family members at risk for sudden death, the need for a new type of personalized care has been identified (Bai, Napolitano, Bloise, Monteforte, & Priori, 2009). A comprehensive approach to care seeks to address the multitude of issues and needs among the at-risk families and allows families to receive coordinated medical care as well as integrated support they need to deal with the complex family issues that may develop. The goal of these clinics is to identify those family members at risk for SCD and offer nursing, medical, and psychosocial support to the family members. This goal is consistent with the American Academy of Nurse Practitioners (AANP) Standard of Practice (Appendix C).

The role of the APN in this interprofessional approach to care delivery is significant because of the collaborative nature of this comprehensive Cardiogenetics Clinic. The AANP recently updated their Standards of Practice for Nurse Practitioners in

2010 (AANP, 2010). One of the standards the AANP stated the APN is to participate as a member of the health and medical care “interacting with professional colleagues to provide comprehensive care” (AANP, 2010, para. iv). As the interprofessional approach to care has developed, there remains a need to evaluate the effectiveness of this model of care from the lived perspective of the family members attending and participating in the clinic.

### **Purpose of the Study**

The purpose of the study is to explore the lived experiences and what is meaningful to the participants of the Cardiogenetics Clinic. The clinic’s aim is to identify and educate family members and provide psychosocial support. To date, there is no data that explores the comprehensive interprofessional approach with regard to families who have experienced an SCD of a family member. This study provides an opportunity to understand the lived experiences of these families.

The lived experiences will be explored by using Newman’s theory of HEC (2008) as the theoretical framework. Newman posited when an individual’s thoughts and feelings are truly being heard in a safe environment a therapeutic intervention has occurred. During this interaction the APN has an opportunity to encourage dialogue that can encourage the process of storytelling. The APN encouraged family members to speak about their lived experience during this time of uncertainty and suffering. When such reflection was prompted, it enabled meaningful events and relationships to be explored during this process of storytelling. This process leads to pattern awareness, promoted healing and encouraged an evolving consciousness.

Engaging the family members who have experienced SCD to share their lived experiences may lead to a deeper understanding of their loss and trauma. The study sought to understand the experiences of families who have had a traumatic loss in their lives. This understanding was sought within the perceptions of these families who were being evaluated and treated in the comprehensive interprofessional Cardiogenetics Clinic.

### **Research Questions**

The study explored the lived experiences of clients who have participated in the Cardiogenetics Clinic. Specifically, it explored the families' response to living with the reality of SCD of a family member and the unknown, uncertain, personal risk for SCD.

The study answered the following research questions:

1. What is the lived experience of families who have experienced the SCD of a family member?
2. What is the meaning of the evolving pattern of the nurse and the participant's mutual process that facilitates HEC in families who have experienced SCD?

### **Definition of Terms**

For the purpose of this study the following definitions will be used.

*Adult cardiologist.* The adult cardiologist is Board Certified in Cardiology and has both PhD and MD academic credentials. The dual academic credentials enable the cardiologist to study genetic material in a research laboratory. The cardiologist evaluates the ECGs and echocardiograms and provides medical treatment for any pressing cardiac concerns for family members over the age of 21.

*Cardiac channelopathies.* This term refers to inherited syndromes that affect the electrical system of the heart. These cardiac arrhythmia syndromes are known to have a

genetic basis and are caused by mutations in ion channel genes. These mutations cause abnormal ionic currents, which can lead to cardiac arrhythmias that may result in SCD. Those syndromes known as cardiac channelopathies include long QT syndrome (LQTS), short QT syndrome (SQTS), Brugada syndrome (BS), and catecholaminergic polymorphic ventricular tachycardia (CPVT) (Bai et al., 2009).

*Cardiogenetics clinic.* This term refers to a treatment center that provides an interprofessional approach to comprehensive care. Members of a Cardiogenetics Clinic include an adult and a pediatric cardiologist, geneticist, nurse practitioner, genetic counselor, social worker, psychologist, and cardiology and genetic research fellows. The clinic offers medical, nursing, psychological, and social care to families that have experienced the loss of a family member to SCD.

*Family members.* This term refers to individuals who are physically, genetically, and/or emotionally involved in families who have experienced SCD and are 18 years old or older.

*Geneticist.* The geneticist in a Cardiogenetics Clinic evaluates the potential risk factors for SCD based on the history and initial examination of the data. The geneticist consults with the adult and pediatric cardiologists to determine and understand the potential risk factors to other family members.

*Genetic counselor.* The genetic counselor in a Cardiogenetics Clinic is a certified genetic counselor and obtains the family history. A family genogram is prepared by asking the family members questions about other family members, relationships, and any information related to unusual history of sudden death in any other family members. Typically, the counselors ask questions up to the first- or second-degree relatives, if

known. They also elicit the history of present illness (HPI), asking the reason and circumstances for the referral. The counselor presents the case to the interprofessional team.

*Health as expanding consciousness.* “In the model of health as expanding consciousness it does not matter where one is in the spectrum. There is no basis for rejecting any experience as irrelevant. The important factor is to be fully present in the moment and know that whatever the experience, it is a manifestation of the process of evolving consciousness.” (Newman, 1994, p. 68).

*Mutual process.* In this study, mutual process is defined as being present to that which is meaningful in dialogue or presencing (Rogers, 1992). Newman (1994) defined it as the interaction between the human field and the environment.

*Pattern or patterning* “is a dynamic process. The continuous change that marks man and his environment is expressed in the continuing emergence of new patterns in man and environment” (Rogers, 1970, p. 63,). Newman (1994) described the process of patterning as occurring “in the interpenetration of human energy fields as transformation takes place. The interference pattern of interacting waves forms a new pattern of the whole” (p. 72). Newman also states that pattern, “is relatedness and is self-organizing over time, i.e., it becomes more highly organized with more information. With increasing information, there is a more complex pattern of relationships” (p. 72). Newman (2008) further stated, “Patterning is a process of recognizing and creating meaning in life. It is enduring and evolving. It is a reflection of one’s relationships with significant people in one’s life and how those relationships change over time” (p. 99).

*Pediatric cardiologist.* The pediatric cardiologist in a Cardiogenetics Clinic is a Board Certified clinician who performs physical examinations on all of the pediatric patients. The pediatric cardiologist consults with the adult cardiologist to assess different risk factors among adult family members. The pediatric cardiologist provides medical evaluation and treatment of potentially lethal cardiac channelopathies in children from infancy to 21 years of age.

*Presence in nursing.* The conscious moment of a nurse's and client's presence through the suspension of judgment and preconceived ideas and being able to recognize their own patterns of interacting with the environment (Newman, 2008). Newman stated that, "It is important that you are fully present with the patient in unconditional acceptance of where they are in the situation" (p. 96).

*Simultaneity Paradigm.* Parse defined this paradigm as man is a unitary being in continuous, mutual process with the environment (Parse, 1992).

*Sudden cardiac death (SCD)* refers to "the sudden, unexpected natural death from a cardiac cause a short time (generally < 1 hour) after the onset of symptoms in a person without any previous condition that would seem fatal" (Zheng, Croft, Giles, & Mensah, 2001, p. 2158).

## **Chapter Summary**

This chapter provided the foundation for the research study. It included the introduction, statement of the problem, theoretical rationale, study significance, purpose of the study, essential research questions, and definition of key terms to be used throughout the study. This chapter described the main goal of the proposed study, which is to explore the lived experiences of the families who have participated in a unique inter-



professional approach to the delivery of care. Gaining insight into how the Cardiogenetics Clinic influences the families may allow interprofessionals to better understand the needs and experiences of family members dealing with SCD and improve the quality of care.

Chapter 2 provides a review of literature, including aspects of clinic design, the theoretical basis of the practice in Newman's HEC and Roger's SUHB, and a comparison of similar research on the experiences of families with similar conditions. The research design and methodology is presented in Chapter 3. Separate sections detail the setting and context of the research, method of data collection, safeguards against hurt or injury to the participants and guarantees of confidentiality and anonymity, and techniques of data analysis.

The results of the study are presented in Chapter 4 and include the demographics of the participants and presentations of the important themes uncovered through the interviews, including focus on health, guilty feelings, ambivalence about genetic testing, family blame and the unwillingness of family members to share information, fear of death. The family's perceptions of their interaction with the Cardiogenetics Clinic are presented, including the negative experience of fragmented care before they were referred to the Cardiogenetics Clinic, affirmation that they were being listened to at the Clinic, the meaningfulness of the experience, and evidence of mutual process as described by Newman (1994). A brief summary of the findings is presented.

In Chapter 5 the findings are related to the theoretical basis for the study and the study's implications and limitations are presented. The themes from the data analyzed are developed into two proposed frameworks. One framework is a model of interprofessional

care delivery. The other model is a framework for transformative nursing praxis. Finally, recommendations for future study and conclusions are offered.

## **Chapter 2: Review of the Literature**

### **Introduction**

The purpose of the study was to explore the lived experiences and what is meaningful to the family participants of the Cardiogenetics Clinic. The families who attended this Cardiogenetics Clinic have experienced the SCD of a family member. This study also explored the integrative collaborative approach to care with an interprofessional team. Gaining insight into how the Cardiogenetics Clinic influenced these families may allow interprofessionals to better understand the needs of family members dealing with SCD and improve quality of care. This chapter presents a review of the literature including an examination of key aspects of the clinic design, HEC theory (Newman, 2008), and research studies that have explored the lived experiences of families with similar disease processes. Evaluating the key aspects of the clinic design is part of the process the families of this Cardiogenetics Clinic encounter. The chapter concludes with a review of research studies that have explored the experiences of families with similar disease processes to establish previous understanding and the need for future research in this area.

### **Aspects of Clinic Design**

The Cardiogenetics Clinic evaluates families that have experienced the loss of a family member due to SCD. Research studies that investigate key aspects of clinic design are important to establish a foundation for the design and evolution of specialized clinic, such as a Cardiogenetics Clinic. In order to understand the purpose of the

interprofessional model of care, the researcher investigated studies that highlighted the current practices of fragmented care and offered an understanding of the need for different models.

Ingles et al. (2008) conducted a study that described key aspects of the interprofessional model of care. The study evaluated the psychosocial impact of specialized cardiac genetic clinics for families with hypertrophic cardiomyopathy (HCM). The purposes of this study were to describe the psychosocial factors associated with attending the specialty cardiac genetic clinic and determine whether psychosocial factors may be predictors of comorbid anxiety and depression in this population. The sample size was 64 respondents, which included 50 who were diagnosed with HCM and 14 who were identified at risk for HCM. All attended this specialty HCM clinic.

Ingles et al. (2008) conducted the study at the Royal Prince Alfred Hospital (RPAH) HCM Clinic located in Sydney, Australia. The HCM Clinic is a specialized cardiac genetic service offering a multidisciplinary approach to the management of individuals with HCM and their families. Individuals attending the RPAH HCM Clinic from September 2003 to September 2006 were invited to participate in the study anonymously. The instruments used in the study included a basic demographic questionnaire, the Hospital Anxiety and Depression Scale (HADS), the Patient Experience Scale and the Patient Satisfaction Scale.

The HADS is a 4-point, 14-item self-report scale that used two subscales to evaluate anxiety and depression. According to the researchers (Ingles et al., 2008) this instrument has been used in hospital settings and to screen for emotional disorders only. The researchers reported that previous studies had used a score of 11 points or higher to

identify those persons with a mood disorder and scores of 8 and 10 points to suggest possible mood disorders (Ingles et al., 2008). A minimum score of 8 points in each of the two subscales was used to identify those subjects with anxiety and depression. The use of this lower cutoff may have resulted in the authors classifying more study participants as depressed or anxious than actually met criteria for these disorders. The authors do not provide actual reliability or validity data for this instrument. However, the authors did state that the HADS scale has been used extensively in the hospital setting and is an important screening tool for emotional disorders.

The Patient Experience Scale was developed specifically for a HCM population. The instrument examines the subject's adjustment to HCM, worry about HCM, understanding of HCM, and involvement in management of their own care. Cronbach's alpha values for the instrument range from 0.67 to 0.91 (Ingles et al., 2008).

The Patient Satisfaction Scale was used to evaluate subjects overall satisfaction with the clinic experience. This instrument was developed for a population of patients with HCM. It has four subscales measuring (a) staff-patient relationship satisfaction with information provided, (b) satisfaction with time spent with clinician, and (c) level of understanding of HCM. The instrument used a 5-point Likert scale for each item.

Results of the Patient Experience Scale of the Ingles et al. (2008) study identified that 66% of those patients with HCM reported adjustment problems related to their diagnosis. Only 10% of patients with HCM stated they had low worry and only 4% of those at-risk subjects reported low worry about their diagnosis. Of the study participants with HCM, 45.2 % suffered from anxiety. In the at-risk participant group 32% suffered from anxiety. Seventeen percent of the subjects in HCM group and 4% of the at-risk

group had scores in the depression range. Statistical analysis found that there was no significant difference between the group with HCM and the at-risk group for either anxiety or depression.

Results of the Patient Satisfaction Survey found that the patient satisfaction scores across all scales (staff-patient relationship, satisfaction with information provided, satisfaction with time spent with the clinician, and satisfaction with level of understanding of HCM) of HCM patients showed statistically significant satisfaction overall in the individuals attending the RPAH HCM clinic, compared to the at-risk relatives. Additionally, the issue of patient satisfaction that was most highly correlated with adjustment among all participants was the level of understanding their diagnosis.

Ingles et al. (2008) identified the small sample size as a limitation of the study. They noted, also, that the use of lower cutoff scores than suggested by the designers of the instrument to identify those persons who were depressed and/or anxious might have resulted in more subjects identified with anxiety or depression. However, the numbers of the participants in the HCM and at-risk relatives were not distributed evenly. The use of a larger sample size and having a comparison group with patients who have not participated in an interprofessional clinic may offer more information in future studies and was recommended by the authors. Among the most significant findings of this study was the concept that gaining an understanding of one's diagnosis was statistically correlated with the participant's adjustment. This offers future programs the knowledge of how important it is to assure that patients understand their diagnosis and treatment plans.

Giuffee, Gupta, Crawford, and Leung (2008) conducted a quantitative study that compared children with asthma to children with LQTS, specifically addressing their levels of anxiety and medical fears. The study also evaluated the mothers of children with LQTS compared to mothers of children with asthma. The sample size consisted of 40 children (25 males/15 females) with asthma and their mothers, along with 7 children with LQTS (4 males/3 females) and their mothers. The groups were further subdivided for a final analysis that compared 10 children with severe asthma with 7 children with LQTS and their mothers. Children were asked to complete the Fear Survey Schedule for Children–Revised (FSSC–R) and the Revised Children’s Manifest Anxiety Scale (R–CMAS). Mothers were asked to complete the Achenbach Child Behavior Checklist (CBCL) and the State-Trait Anxiety Inventory.

All families participating in the study (Giuffee et al., 2008) were followed at the Alberta Children’s Hospital in Alberta, Canada. The results indicated that children with asthma had higher scores on the FSSC–R for more medical fears as well as fear of minor injury and small animals ( $p = 0.001$ ) compared to children with LQTS. There was no difference noted in overall anxiety between the two groups of children. However, the children with LQTS had higher rates of internalizing behaviors (anxiety, depression, worry) than the children with asthma ( $p < .042$ ).

Mothers of children with LQTS reported higher State-Trait Anxiety Inventory scores ( $p = 0.001$ ) as compared to mothers of children with asthma. The overall anxiety scores for both groups of mothers were not statistically different. When the groups were further divided into the 10 mothers of children with severe asthma and their levels of anxiety were compared to the mothers of children with LQTS, the results showed that the

mothers of children with LQTS had higher overall anxiety ( $p < .001$ ) and State-Trait anxiety ( $p < .025$ ) than the mothers of children with severe asthma.

The study (Giuffee et al., 2008) suggested that mothers of children with LQTS live with a higher level of anxiety because they fear their child may suddenly die. Although not addressed by the researchers, the findings of this study must be considered with caution due to the small sample size and, specifically, the relatively small number of patients with LQTS. Future studies gaining a deeper understanding of these families' experiences offers nursing the ability to enhance future care for these at-risk families. Gaining an in-depth understanding of the lived experiences of these families offers nursing the opportunity to understand what these families feel and identify what the needs of these families are.

### **Health as Expanding Consciousness Theory**

Newman's (1994) nursing theory, HEC, is the proposed framework for this research study. Contrary to the orientation of the biomedical model, Newman's theory has a holistic nature. She views her theory as evolving from Martha Roger's Science of Unitary Beings (SUHB) theory, which regards the "patterning of persons in interaction with the environment basic to my view that consciousness is a manifestation of an evolving pattern of person-environment interaction" (Newman, 1990, p. 38). Fawcett, Watson, Neuman, Walker, and Fitzpatrick (2001) classified Newman's theory as a grand theory. Grand theories are broad in scope and comprehensive in order to encompass "views on person, health, and environment to create a perspective of nursing" (LoBiondo-Wood & Haber, 2010, p. 578). Newman (1994) classified her theory as a unitary-transformative grand theory. The theory assumes that human beings are different



than the sum of their parts. They are self-regulating and self-evolving, embedded in and interacting with the larger energy system known as the universe, and known for their ways of being, patterns of energy, and distinctness from others.

Newman (1994) echoed Rogers' view that health and illness are contained within what is termed a unitary process, meaning that human beings are related to the larger universe in mutual process. Health and illness are no longer seen as part of a continuum. The idea that health is a higher state of consciousness and illness is a lower is not consistent with this theory. Newman's theory reflects a paradigm shift of what is considered the experience of health. Central is the idea that illness is not a separate function, but is a dimension of the evolving pattern of patient-environment interaction (Newman, 1994). Within HEC, the nurse-client relationship is not fragmented or hierarchical but is a partnership that encourages exploring the patterns that exist for individual experiences. These patterns include the experience of health and expanding consciousness. Because the APN is a nurse, the APN's role includes assisting the family to understand the overall evolving patterns.

A goal is for the APN to help the family member see that the pattern of health is integral within the broader experience of life and consciousness. One unique aspect of the theory is that APNs and families may be changed or transformed by this process. The nurse or nurse-researcher engages the participant in a dialogue about events most important to them, and the nurse creates an opportunity for "reflection, awareness, and potential insight" (Picard & Jones, 2005, p. 13). Identifying patterns in life, patterns that can affect health, can lead to an expansion of consciousness (Newman, 1994). Both the APN and the client are affected by patterns and create a healing unit rather than a

traditional expert-patient relationship. The healing unit creates a partnership where both parties are needed to develop insight and move toward recognizing the patterns relevant to a person's life. Because the APN experiences a profound reflection in mutual process on his or her life and insight, the APN as well as the family member experience an expansion in consciousness.

Falkenstern et al. (2009) conducted a study that sought to develop knowledge about the nurse-client process of facilitating health in families who have a child with special needs. This qualitative study asked, "What is the evolving pattern of the nurse-client process that facilitates health as expanding consciousness in families who have a child with special needs?" (p. 267). The theoretical framework used for the study was Newman's theory of HEC. The family was defined as one caretaking adult and one child living within the same household. At least one child in the family required special care needs and was at least 5 years old. A total of seven eligible families participated in the study.

The APN met twice with six families and four times with one family. A total of 16 interview sessions produced 500 transcribed pages. Interviews with Family 6 and 7 confirmed the APN's judgment that the pattern of the whole of the nurse-client process was emerging. The settings for the interviews were established at a time and place that was convenient for the families. Meetings spanned seven months, with most meetings occurring during the first four months. The APN was identified as the instrument. Newman's (1994) recommendation of speaking from the center of truth allowed the APN to relax in the process. Immediately after each meeting, the APN started a computer file to record the observations of the family's physical environment: their sense of time,

space, and movement. The APN noted her own feelings, insights, and sense of time, space, and movement. The APN became synchronized with the rhythm of the family as future meetings occurred (Falkenstern et al., 2009).

The APN used hermeneutic dialectics to make sense of the transcribed interviews. Hermeneutics is the search for meaning and understanding through interpretation. Dialectics refers to the process of interview between the researcher and the participant. After the APN reflected on the taped and transcribed dialogue, she completed a narrative summary of the family's meaningful events. The pattern of the nurse-client process emerged and became meaningful within the APN's consciousness. The evolving pattern of the nurse-client process became connecting with each family, forming a partnership for interview, creating a sense of freedom for limitless expression, feeling a sense of timelessness for awareness and insights, and resonating with each other as one for transformation (Falkenstern et al., 2009).

### **Experiences of Families with Similar Conditions**

A qualitative study conducted in 2005 (Farnsworth et al.) explored the fear of death and quality of life in 58 patients with LQTS. Data from this study was derived from a pilot study done by the authors in 2002 that was never published. The data collected in the pilot study was reevaluated with a focus on questions pertaining to fear of death and quality of life in the patients who had been diagnosed with LQTS.

In the pilot study, 58 subjects with genotyped LQTS (LQT1, LQT2, or LQT3) were asked to answer seven open-ended questions about living with LQTS. The questions included fear of death, quality of life, the impact of education on decisions about care, and the impact of the diagnosis on insurance. Farnsworth et al. (2005) conducted a

secondary analysis of the 2002 pilot study that described the experiences of parents who have a child with LQTS.

The researchers' secondary analysis evaluated responses from 31 parents of children with LQTS. The study reported what life was like for parents who have children with LQTS. Data was sorted, analyzed, and categorized into themes relating to fear of death, quality of life, uncertainty, and responses relating to education (Farnsworth et al., 2005). The researchers presented three most common themes among the parents and families of children with LQTS, which were fear of death, quality of life, and uncertainty.

When evaluating the first common theme of the fear of death, the authors noted that 21 of the 31 parents stated they did not fear their own death but 19 of the same 31 of these parents expressed fear of their children dying. Additionally, 12 of 31 parents reported no fear of their child dying. It should be noted that all 12 of these children had no symptoms of their disease (Farnsworth et al., 2005). It may be that these parents of asymptomatic children may not have experienced the potential reality of their child's death as other parents may have.

Parents reported (Farnsworth et al., 2005) fear of death, which they managed by lifestyle changes made by the families. Examples of lifestyle changes included: parents would provide cell phones to their children to check on them frequently; parents purchased a portable defibrillator that they kept at home and took with them everywhere the child went, such as sports fields; and families educated other family members and school personnel on what to do in case their child passed out. Parents, also, taught their children how to listen to their bodies and not ignore any unusual feelings and to seek immediate help. The key findings of this study included parents decreasing fear by

empowering themselves and their children. Parents educated the community and health care professionals regarding the signs and symptoms of LQTS syndrome, and supporting the families suffering from LQTS was a way family's perceived empowerment.

Quality of life was the second common reoccurring theme described in the study (Farnsworth et al., 2005). The most significant impact on quality of life included decisions families must make to avoid triggers that can precipitate lethal cardiac arrhythmias and decisions made about treatment options, such as knowing the side effect of medications and implantable devices. Treatment options and triggers are different based on the different types of LQTS.

The third common theme explored in this study (Farnsworth et al., 2005) was uncertainty. Upon the initial diagnosis the families experienced uncertainty, but once they began to understand and manage LQTS, they were better able to not let the emotion take over their lives. The families revealed that with time, knowledge, and treatment options, uncertainty was not an ongoing theme.

The key findings of the study were the need for education of families, health care professionals, and the community in the diagnosis of LQTS (Farnsworth et al., 2005). This study demonstrated how significantly many aspects of the lives of all family members are affected by LQTS. How the newly developed interprofessional clinics influence the lives of these families has not yet been fully researched.

In a personal investigation, Picard (2002) explored her family's experiences related to the death of her brother in 1953 from sudden infant death syndrome (SIDS). Picard's study was a process of cooperative inquiry among her family members to uncover the story of her brother and the ways his death resonated within her family. The

sample participants were Picard's family members: her mother, father, five sisters, paternal aunt, maternal aunt, and Picard, herself. Family participants were invited to share what he/she remembered about her brother's death and to reflect on the meaning his death and its impact on the family. The participants were also invited to share any writings or materials they encountered during the dialogue. All conversations were audiotaped and transcribed. Dialogues lasted approximately one-and-a-half hours. The theoretical framework Picard (2002) chose for her study was Newman's HEC theory.

In this process, Picard stated that she offered her presence as both a family member and nurse researcher. Picard noted, "Although the inquiry was focused on one part of the family story, the researcher recognizes that this is a particular expression of a much larger whole" (p. 243). She also stated that the family consciousness expanded through unbinding energy through the process of dialogue. The process of dialogue was the therapeutic nursing intervention that expanded the family consciousness.

The outcome at the end of this process, noted by Picard (2002), was an increased experience of family connectedness. She also described a booklet that was made of the transcripts of the dialogue, pictures, poems, essays, and personal journal reflections. Copies were given to the participants and they were invited to read their own stories. Ten days after receiving the booklets, the participants came together to reflect on the stories as a family. Picard observed that this collaborative process made it possible for her family to express feelings of grief, sorrow, energy shifts, and insight. It incorporated the praxis mode of reflective practice and growth for the researcher and her family.

Picard's (2002) study is an example of a family that could be referred to the Cardiogenetics Clinic. The sudden loss of an infant to SIDS is a very common referral. In

fact, in Picard's discussion she encourages the use of a genogram as a praxis tool to identify family loss issues, old or new when other symptoms are manifested. The dialogue shared in this study could be an example of some of the processes encountered by families in the Cardiogenetics Clinic. Another key aspect of this study was the use of dialogue and presencing to expand the family consciousness.

Hendriks et al. (2008) conducted a quantitative prospective study with 134 participants in families at risk for SCD. The study was conducted in a multidisciplinary cardiogenetic outpatient clinic in the Netherlands situated in all university hospitals. The purpose of the study was to investigate the extent and course of disease-related anxiety and depression caused by cardiac genetic testing for LQTS. There were 77 adult relatives and 57 of their partners of LQTS index patients in whom a causative mutation in one of the three major LQTS-causing genes was detected. The 77 adult relatives wanted to be tested to determine their risk for an LQTS-causing gene. None of the 77 relatives had been clinically diagnosed with LQTS before. In addition to the 77 relatives tested, 57 of their partners were tested, as a theoretical control group. The prospective study design consisted of data assessments within two weeks of the first consultation (T1) and two weeks (T2) and 18 months (T3) after the genetic testing result disclosure.

Disease-related anxiety was assessed with the 15-item Impact of Event Scale (IES). This instrument measures anxiety as a result of a stressful event, such as being at risk for LQTS. Scores of 0 to 8 indicate minor anxiety, 9 to 19 moderate anxiety, and 20 or above clinically important anxiety. Depression was assessed with the 21-item Beck Depression Inventory (BDI). Scores of 0 to 9 are considered normal, 10 to 16 suggest

mild depression symptoms, and scores higher than 16 suggest moderate to severe depression symptoms.

During the initial phase of the study (Hendriks et al., 2008), the participants were evaluated in a combined consultation by the cardiologist and clinical geneticist. Based on the ECG results and the clinical/family data, a presumptive diagnosis was given. Pairwise comparisons among the study patients and their partners were preformed. The four clinical groups were performed during the three points in assessments.

Patients were segmented into four different clinical groups, those with abnormal ECG who proved to be carriers, those with uncertain ECG who proved to be carriers, another group with uncertain ECG's who proved to be noncarriers, and those with a normal ECG who proved to be noncarriers. Blood for genetic testing was drawn at the first visit. The result of the genetic testing was disclosed at the second visit, approximately eight weeks after the initial visit. Psychological support was made available at the patient's request.

The study (Hendriks et al., 2008) noted subjects with an abnormal ECG who proved to be carriers proved to have mean disease-related anxiety scores that were statistically significant during the first two assessments and on the third assessment expressed a moderate disease-related anxiety scores.

The subjects in the second clinical group with an uncertain ECG who proved to be carriers expressed mean disease-related anxiety at the first two assessments. This group went on to have a moderate disease-related anxiety at the third assessment. This group also showed a higher depression scores compared to the participants that had normal or abnormal ECG irrespective of future carrier status.



The subjects in either the normal or uncertain ECG group that proved to be noncarriers had moderate disease-related anxiety scores during the first assessment. This anxiety score decreased once the genetic results were disclosed, and the anxiety scores dropped in the next two assessments. Comparisons among the four subgroups revealed that the first assessment with an uncertain ECG showed a higher depression score than subjects who had a normal or abnormal ECG, irrespective of future status of being a carrier or not (Hendriks et al., 2008). The study reported that subjects with an uncertain ECG showed a higher depression score than others. This suggests the need for ECG results to be given to the patients at the time of visit.

### **Summary**

The research indicated that families that had a SCD of a family member do experience anxiety related to the possibility of carrying the genetic mutation of LQTS. These studies (Ingles et al., 2008; Giuffee et al., 2008) support the need for an interprofessional model of care by providing data that encourages the collaboration of cardiologists, geneticists, and genetic counselors.

Previous research that was grounded in Newman's (1994) HEC explored the nurse-client relationship (Falkenstern et al., 2009). This nursing theory provided the theoretical framework and basis for the research questions for this study. Falkenstern et al. (2009) and Newman's HEC theory support and describe the evolving pattern of the nurse-client process and how the process facilitates health as expanding consciousness.

The studies that are similar to the experiences of families with similar conditions to SCD are key in exploring the different aspects of emotion. Farnsworth et al. (2005) found that fear is a common theme of families with LQTS. Hendriks et al. (2008) study

found that anxiety and depression are key emotions when patients are evaluated for LQTS. Picard (2002) found the use of dialogue and presence was able to expand family consciousness during the qualitative exploration of her sibling's death due to SIDS. These studies have shown that fear, anxiety, and depression are associated with the process of being tested for a potentially life-threatening disease, such as LQTS (Farnsworth et al., 2005; Hendriks et al., 2008). The research has shown that by exploring these different emotions and lived experiences through dialogue and presencing, expanding consciousness may be achieved (Picard, 2002).

## **Chapter 3: Research Design Methodology**

### **Introduction**

The purpose of the study was to explore the lived experiences of families who experienced a loss of a family member from a sudden cardiac death (SCD) episode and have been evaluated in the Cardiogenetics Clinic at the Children's Hospital at Montefiore (CHAM). Because Cardiogenetics is a new and evolving field, little is known about the medical and psychosocial needs of these families (Farnsworth, Fosyth, Haglund, & Ackerman, 2005). The study utilized a qualitative phenomenological approach to explore the lived experiences of family members who have SCD. A sample was drawn from the families that had been evaluated in the Cardiogenetics Clinic and participated in the National Institute of Health (NIH) study also conducted in the Cardiogenetics Clinic. Interviews were conducted; phone conversations were a part of this study before and after the interview process. The APN also journaled experiences before and after the interview process. The participants are the source of knowledge and were asked to engage in dialogue to explore their lived experiences and what it means to them. The following questions were asked in the interview:

1. Tell me the story of your family member's experience with SCD?
2. Tell me the story of your experience with the Montefiore Cardiogenetics Clinic?

## **The Research Context/Setting**

The study was conducted in the Cardiogenetics Clinic at the CHAM, a metropolitan hospital in the Bronx, New York, which cares for underserved children and families in the New York City area with cardiac conditions. The Cardiogenetics Clinic meets the third and fourth Friday of every month from 8:30 to 12:30 a.m. The interprofessional team meets in the conference room next to the consultation rooms and consists of an adult and pediatric cardiologist, a geneticist, an APN, a psychologist, and a social worker. The APN reviews the scheduled families that are due to arrive. The APN has data that has been collected from telephone interviews on the new families and brings the charts of any families that are scheduled for follow-up visits. Figure 3.1 illustrates the traditional linear clinic process that the APN participates in during the families' first visit to the Cardiogenetics Clinic.

The major goal of this interprofessional team approach is to provide the most comprehensive care to the families who are referred following the SCD of a family member. The first team member to make contact with these families is the APN. The APN first telephones families and explains the interprofessional approach of this clinic and then schedules the families based on individual history. If necessary, the APN contacts the medical examiner's office in order to gain information such as autopsy reports and specimens such as genetic material. The APN is present with the family for the initial visit and answers any questions and/or concerns. The APN is the key contact regarding follow-up testing and visits.



*Figure 3.1. The Linear Clinic Process.*

Once all of the consultations are completed, the APN concludes the visit by addressing questions or concerns that have arisen during the visit. The APN also schedules and performs any testing that is indicated such as electrocardiograms and echocardiograms. The APN provides contact information and any specific handouts that pertain to the specific family needs. During the process of this study this linear clinic process has evolved into an ongoing holistic interaction with the interprofessional team.

The APN's role evolved into the role of a researcher during the process of conducting this study. Newman's HEC theory guided the APN during the interview process. The utilization of HEC encouraged the family member not only to explore their

feelings and also understand their expanding pattern of consciousness, rather than focusing on health and illness. One of the primary assumptions of HEC is that recognizing that the overall pattern of health potentially facilitates the expansion of consciousness. HEC is a “way of being with the client-a way of offering the client an opportunity to know, be known, and to find their way” (Newman, 2008, p. 16).

The APN’s role evolved through presencing with these participants; as the participants explored their experiences with the APN, the nurse and participant became integral. Newman (2008) described this process as the “nurse and patient coming together and moving apart in process recognition, insight, and transformation” (p. 35). This is the process the APN had encountered and lead to the evolving consciousness of both the APN and participant.

### **Research Participants**

The participants for the study consisted of families participating in the Cardiogenetics Clinic at the CHAM, in the Bronx, New York. Family members are defined as individuals who are genetically and emotionally involved in these families and are 18 years old or older over a six-month period.

The study was part of a larger National Institute of Health (NIH) study being conducted at CHAM. The larger study consisted of conducting focus groups for families who have been seen at the Cardiogenetics Clinic to evaluate the ethical and social implications of receiving this genetic information in this comprehensive approach. All participants interviewed for the NIH study had been evaluated at the Cardiogenetics Clinic and were also participating in a larger NIH study. The families in the NIH study were invited to participate in this study and which included face-to-face interviews,

telephone discussions and the APN journaling after the interviews to engage in dialogue regarding their lived experiences. The participants for this study were selected on the basis that they had returned to the clinic setting for a follow-up visit after reviewing the testing results.

### **Data Collection**

The APN obtained a list of the NIH focus group study participants. Each participant was called and invited to participate in an interview with the APN to explore the lived experiences of the participant. Once the participant had agreed, an interview date and time was scheduled at a time convenient for the participant. Twelve individuals were called, five answered the call and agreed to participate. The other seven were left messages and called a second time but did not respond to the second message that was left on their voicemail. The interviews were conducted in a designated conference room at CHAM after the participants had signed the informed consent (Appendix D). The role of the APN was to create a therapeutic, nonjudgmental environment for a safe and meaningful dialogue.

The APN strove to suspend preconceived judgment or ideas and was open to new information that emerged. The APN encouraged the family member to speak about the lived experience during this time of uncertainty and suffering. Since the goal of phenomenological enquiry is to fully describe a lived experience, this research methodology explored the lived experiences of the families in this study.

During the interview the dialogue exchange was audiotaped. Immediately after the interview the APN recorded, in a journal, any observations that were made of the families' physical environment, movement, and nuances of conversations. The

interviews were scheduled for one hour and all the interviews stayed within the one hour time frame. Once the interview concluded the participants were given the opportunity for a follow-up interview but none scheduled. The APN recorded any personal feelings, insights, movements, or observations. The APN submitted the audiotape to the transcriber.

**Protection of human subjects.** This study explored the lived experiences of family members who have had a loss of a member of their family to SCD. The possible risks to these family members included anxiety, feeling upset by thinking about the loss of their family member, and emotional distress. A designated family psychologist agreed to be available to speak to any individual demonstrating significant emotional distress and/or requesting someone to speak to regarding his/her feelings during the study.

Any participant that became upset during the time of the interview process was offered the opportunity to speak to the designated family psychologist. One referral was made during this interview process. A participant became emotional during the discussion of a deceased family member. The psychologist was called and a discussion and referral eased her feelings of sadness. There were no apparent physical risks for the individuals participating in this study. Confidentiality and anonymity of the participants was maintained at all times.

### **Data Analysis**

In phenomenological research the optimum method for data collection is unstructured one-to-one interviews (Mapp, 2008). The goal idea of qualitative research is to examine the meaningful and symbolic content of qualitative data. A phenomenological process (LoBiondo-Wood & Haber, 2010) was used to analyze the data from the



interview transcripts from the audio recordings of each interview with the participants for this study. The researcher reviewed all transcripts from the interviews and reflected on each interview in order to gain an understanding of each participant's experiences. The researcher then analyzes the interviews again identifying common themes, ideas and concepts from the experience of listening to each participant's responses. Insights into the participant's experiences emerged via looking for patterns and meanings in the participant's ideas, thoughts and feelings. Coding was used to evaluate the data for themes, ideas and categories based on themes, topics terms and key words found in data identify common themes that emerged from reading each participant's responses during the interview process. The codes were given meaningful names that gave an indication of the idea or concept that underpins the theme or category. Any parts of the data that related to a code specific identified theme or topic are coded with the appropriate label. This process of coding involved close reading of the text. If a theme is identified from the data that does not quite fit the codes already existing then a new code is created. As the researcher read through the data set the number of codes evolved and grew as more themes became apparent. The final set of themes was identified, labeled and examples of each theme were offered in the explanation of these themes.

The data from the interview was recorded on audiotape and transcribed by a professional transcriptionist. Once the audiotaped data was transcribed the researcher reviewed the data for key words. Key words were noted in the transcripts in order to identify and code emerging themes. The interview questions explored the lived experiences of the families that have experienced SCD. These experiences were transcribed and analyzed for themes and meanings, allowing the experience to be

understood. Once the APN analyzed a transcription the journal notes related to the transcription were reviewed. This was repeated for each participant transcription and journal notes. This process was repeated until saturation was achieved.

LoBiondo-Wood and Haber (2010) suggested that the researcher is the primary data collection instrument. It is important for the researcher to be self-reflective and set aside any prejudgment. These authors suggested that the interview begin with a social conversation aimed at creating a relaxed and trusting environment (LoBiondo-Wood & Haber, 2010). Prior to the start of the interview the researcher must explain to the participants that the process may take some time to fully focus on the experience. The participant's perception that the APN is supportive and trustworthy allows them to describe their experiences without bias until data saturation is achieved.

### **Summary**

The purpose of this study was to explore the lived experiences of families that had participated in the Cardiogenetics Clinic. The researcher conducted one-on-one interviews with family members who had experienced SCD of a member of the family and participated in the NIH focus group conducted in CHAM. The study sought to explore the lived experiences of the families who had experienced a new, interprofessional approach to care. The key element in this process was the APN and family member engaging in dialogue. By exploring the experiences of these family members within a therapeutic, nonjudgmental environment, the APN was better able to facilitate their evolving patterns (Falkenstern et al., 2009). Gaining insight and understanding into how the Cardiogenetics Clinic influences the families may allow

interprofessionals to better understand the needs and experiences of family members dealing with SCD and may improve the quality of care.

## **Chapter 4: Results**

### **Introduction**

The research study was conducted to examine the lived experiences of families who have experienced sudden cardiac death (SCD) of a family member. This study was part of a larger NIH study entitled Ethical and Social Implications of Genetic Testing in the Case of Unexpected Deaths. The participants were selected based on their initial participation in this NIH study. There were 12 participants of those NIH subjects that were invited to participate in this study. Five responded to the invitation and agreed to participate in the study. The five participants were invited to be interviewed during June and July 2011. The face-to-face interviews were conducted in a designated room at the Children's Hospital at Montefiore (CHAM).

The APN researcher conducted the initial interview and telephone conversations before and after the interview process with each participant. As part of the interview process the APN researcher kept a journal of these interactions and conversations. The participants were asked two specific questions, "Tell me the story of your family member's experience with SCD?" and "Tell me the story of your experience with the Montefiore Cardiogenetics Clinic?" After each interview was completed, the researcher kept a journal describing these interactions, participant's responses, and observations made during the interview process.

The research questions that guided interviews with the participants were

1. What are the lived experiences of families who have experienced the SCD of a family member?
2. What is the meaning of the evolving pattern of the nurse and the participant's mutual process that facilitates HEC in families who have experienced SCD?

To answer these research questions individual family members who have suffered a SCD episode of another family member and who have attended the Cardiogenetics Clinic were interviewed. Demographic information and interview results are summarized in this chapter. The results of the interviews are presented as several themes and further explored within the context of Newman's (1994) theory of HEC.

### **Demographics**

The interviews were all conducted in the CHAM. The interviews were completed with five adult participants which included one male and four females. All of these participants had been evaluated by the Cardiogenetics Clinic for genetic risk for SCD and were part of the original NIH study. The researcher interviewed each participant individually. These interviews were completed at a time agreed upon between the APN and family member that allowed them ample time to spend exploring their experiences. Each interview was transcribed word for word and later used by the APN along with her journal notes and observations in order to identify themes, concepts, and common feelings and experiences.

Demographics for each participant include age, gender, race or ethnicity, and the relationship to the SCD participant. A summary of the demographic data of each participant is presented in Table 4.1.

The first participant (P1) was a 55-year-old Latina mother who lost her husband to SCD and has a 21-year-old daughter who was evaluated at the Cardiogenetics Clinic. The father died 10 years ago and postmortem specimens were not saved by the medical examiner. Because her daughter had been having symptoms of palpitations and episodes of near syncope, she had genetic testing for LQTS. The results of her genetic testing were negative for LQTS.

Table 4.1

*Demographic Data of Study Participants*

Participant	Age	Gender	Race/ethnicity		Relationship to participant	Time from SCD to interview
1	55	female	Latina		Husband died suddenly 21-year-old daughter alive	10 years
2	57	female	African-American		26-year-old son died 6-year-old grandson died and 8-year-old granddaughter alive	2 years
3	28	female	African-American		28-year-old husband died 8-year-old daughter alive	1 year
4	51	female	Latina		12-year-old adopted boy unknown death in family	1 year
5	31	Male	Latino		28-year-old wife died suddenly 5-year-old daughter and 7-year-old son	1 year

The second participant (P2) was a 57-year-old African-American woman whose son and grandson died of SCD. Both her son and grandson had postmortem testing and were genetically positive for LQTS. Her granddaughter underwent genetic testing through the Cardiogenetics Clinic and was found to have the same gene mutation for LQTS as her father and brother. She is currently being treated with medication and had an internal defibrillator (ICD) surgically placed.

The third participant (P3) was a 28-year-old African American mother of an 8-year-old girl whose father died one year ago and had tested positive for LQTS during a postmortem evaluation. Her daughter was tested at the Cardiogenetics Clinic and found to be positive for the same LQTS gene mutation as her father. She is being treated with medication and has an ICD.

The fourth participant (P4) was a 51-year-old Latina mother of a 12-year-old adopted boy who was evaluated for multiple episodes of syncope and was sent for evaluation for LQTS. Due to the inability to evaluate the family history, genetic testing for LQTS was initiated. The results indicated the LQTS gene mutation. Currently the child is being treated with daily medication and will continue to be followed by the members of the Cardiogenetics Clinic.

The fifth participant (P5) was a 31-year-old Latino who lost the mother of his two children at the age of 28 to SCD. His children are now 5 and 7 years old. The mother was being evaluated for LQTS but died before genetic testing or treatment could be initiated. Due to this history the mother was genetically tested postmortem and was found to be positive for LQTS. The father brought his children to the Cardiogenetics Clinic to be tested for the LQTS gene mutation. Both of his children were found to have the mutation

for LQTS. They are both being treated with daily medication and followed by the members of the Cardiogenetics Clinic.

### **Question 1: Lived Experiences With SCD**

On first meeting with the APN family members were asked to “Tell me the story of your family member’s experience with SCD.” The purpose of this question was to explore the lived experiences of the family members who had experienced the sudden death of a family member. The question elicited several themes as the individuals told their stories. Five themes emerged from the questions: focus on health, guilty feelings, ambivalence about genetic testing, family blame, and fear of death.

**Focus on health.** The World Health Organization defined health as “complete physical, mental, and social well-being and not merely the absence of disease” (2007, para. 2). This is inconsistent with Newman’s HEC theory. Newman (1994) defined health as a process of developing awareness of self and environment, ongoing and evolving. Newman’s definition implies that health is constant and evolving not static and complete.

When exploring the theme of focus on health, four of the five participants engaged in a discussion regarding the health of the deceased member or their own health and health behaviors. The family members discussed the health habits of the deceased and seem to associate these habits with their death from LQTS. Other family members seemed to struggle with the concept of seeing their loved one living a healthy life and yet dying suddenly. Some of the family members used this experience to change their own health behaviors to living a healthier lifestyle.

P5 stated how the loss of the mother of his children from untreated LQTS changed his behavior. He described how “focusing on my health and food choices and



eating differently made me healthier.” His stated that he had lost weight, which he associated with “being healthier” and is now encouraging his children to make healthy food choices. Although issues such as cholesterol, lipids, and fatty foods have not been linked to death for LQTS, P5 felt that by making healthy food choices he may be able to help his children avoid suffering the same fate as their mother. His children are genetically positive for the LQTS mutation that caused the sudden death of their mother. He stated, “If she didn’t pass away, it [eating healthier] never would have crossed our minds. So I’m happy that I can educate them.”

Additionally, P5 mentioned his focus on medication compliance and follow-up within the clinic for ongoing evaluation as health behaviors that can help avoid SCD in his children. The many telephone conversations with P5 and the APN supported the perception that this father is determined to keep his children safe by getting their medication on time and coming for regular follow-up appointments. During one telephone conversation he said that he wants to do all that he can “so my children would not suffer the same fate as my wife did.” He seemed to feel that by promoting positive health behaviors he could prevent his children dying from LQTS. The APN provided positive feedback, supportive listening and encouraged this healthy lifestyle changes and acknowledged the importance of following up for close monitoring.

Another interview focused on health related to her son’s death. P2 stated that her son was “very healthy and health conscious and everything, unlike me.” P2 felt that she did not live a healthy lifestyle, like her son, yet he died and she was still living. The disassociation between “being healthy” yet dying suddenly seemed to be confusing to this mother. This is a mother who lost her son and grandson to a SCD from undiagnosed

LQTS. Through the discussions with the APN regarding her feelings of loss and struggling to understand how her “healthy son and grandson” could suddenly die, P2 was able to recognize the importance of having her granddaughter tested in order to promote her health. P2 was concerned and wanted to know if her granddaughter was positive for the gene and if she could help keep her healthy through the treatments offered. The APN encouraged P2 through this process of grieving the loss of her son and grandson and focusing on her granddaughter’s health.

P1 struggled with the thought that her husband had died suddenly but “was absolutely healthy, and his cholesterol count, I’ll never forget, was 37 when he passed away and he had absolutely no symptoms.” P1 described the feeling of being comforted with the knowledge that he was “healthy” according to the criteria typically used to define health, yet he could die suddenly at 38 years of age. Her husband did not have genetic testing due to the unavailability of testing 38 years ago. Although, P1’s adult daughter was healthy growing up, her mother became concerned when her adult daughter experienced symptoms of palpitations and episodes of near syncope. She had her daughter evaluated in the Cardiogenetics Clinic to assess her risk of SCD. P1 had become aware that even though she considered her daughter to be “healthy” she realized she could look healthy but die suddenly.

P4 stated that her son had “never been a sickly kid. If he sees the doctor once a year it’s a lot, besides his physical, no ear infections, throat infections, none of that.” She emphasized this fact because she could not understand his new symptoms. She had adopted this child at the age of 2 months and at age 9 he began to have symptoms of dizziness and syncope. The child’s family history is unknown but P4 had described many

of his health habits over the 9 years. The observation of “how healthy he was” was repeated throughout the interview process.

In summary, the four of five participants experienced feelings regarding the health of the deceased member of their family or their own health and health behaviors. The experiences of health lead to the participants’ awareness of their own health habits. Some participants focused on the experiences of the deceased family members’ health habits before their death. The discussion of health has led to their awareness of self and environment.

**Guilty feelings.** The Gale Encyclopedia of Psychology defined guilt as “an emotional state produced by thoughts that we have not lived up to our ideal self and could have done otherwise” (Daeg de Mott, 2001). The feeling of guilt is another reoccurring theme in this study. Three of the five interviews explored guilty feelings the participants felt. The participants recalled possible signs or symptoms after the SCD of the family member. There were other participants that could not recall any observations and felt guilty for not being aware of possible signs.

During P1’s interview she recalled that she remembered her deceased husband “looking grayish; his color looked gray in the last few weeks of his life. . . . And I didn’t see it.” She expressed concern about her daughter’s health, who was 21 years old and having symptoms of palpitations. She did not want to miss any signs. During a conversation in a clinical setting she mentioned that this was why she brought her daughter to be evaluated at the Cardiogenetics Clinic. P1 has always been very involved in her daughter’s care. She comes to every visit and her daughter looks to P1 for advice.

The presence of guilty feelings was also expressed in an interview with P2, who said, “I don’t know if T [her daughter] was talking about it [LQTS] and I didn’t even pay attention to the term, but when ML’s [her granddaughter] mom mentioned it I became more familiar with it. . . . But before that I just didn’t pay attention to it.” P2 felt guilty about not understanding the unfamiliar term of LQTS and how it could affect her granddaughter. P2 understands the terms and this process evolved as she had visited the Cardiogenetics Clinic for evaluation and follow-up. P2 wanted do to as much as she could to help her granddaughter by participating in interviews and educating others in her family. Her feelings of guilt appeared to be transformed to feelings of understanding during the interactions with the APN.

In the interview with P5 he stated that he “felt bad. I felt guilty at one point that it was told to us a while back about her having a pacemaker, and that if she did have a pacemaker this definitely would have saved her.” He appeared to struggle with the feelings of guilt because he had not understood enough to protect her. This may be why he is making it his life’s mission to protect their children with knowledge and understanding about LQTS.

In summary, three of five participants experienced feeling of guilt. They explored these feelings when discussing the struggles their ill family members experienced. Some felt guilt at times when they missed a sign or symptom of illness because of their lack of knowledge. These discussions led to awareness and expression of the feeling of guilt.

**Ambivalence about genetic testing.** Ambivalence has been defined as the coexistence within an individual of positive and negative feelings towards the same action, simultaneously drawing him or her in opposite direction (“Ambivalence”, 2006).

The APN noted many of the participants demonstrated feelings of ambivalence surrounding the decision regarding having the genetic testing done. All the study's participants and their family members had genetic testing for the LQTS gene mutation. The participants, however, continued to express ongoing feelings of ambivalence about genetic testing. Genetic testing was performed on three of the children of the participants and two participants had testing performed on a family member postmortem. The family members all consented to the genetic testing, but appeared to be conflicted during the decision-making process.

P1 explored her ambivalent feelings toward her adult daughter's decision regarding genetic testing when she said "I just remember feeling overwhelmed and knowing that deep down, I wanted her [daughter] to have the genetic testing because I wanted to know but at the same time was scared of finding out if she was positive because I would not know what to do. But she [daughter] felt because the disease is more common in men and she felt fine, she did not need to be tested." During many discussions with this mother she expanded on this ambivalence and related anxiety in great detail. She said that "there was too much information given to us, and it was difficult helping my daughter make the right decision [regarding genetic testing]." She felt very involved to this decision-making process even though, ultimately, it was her adult daughter's decision.

Feelings of ambivalence were clearly stated by P5 as well. He stated, "There's always a small part of you that you don't want to find out [results of genetic testing]." He demonstrated significant positive and negative feelings towards deciding whether or not to test his 2 children who had lost their mother to SCD. During the discussions with P5 he

stated although he had concerns about whether or not to test his children, he had significant guilt over the fact that he had not supported his wife in her quest to determine her risk for SCD prior to her death. He stated that this experience of losing his wife and his guilt over not “being there for her as I should have” lead him to want to have his children tested and do “everything I can to make sure they live the life my wife won’t be able to.” In P4’s interview, she stated her ambivalence very clearly and succinctly when she commented, “my partner and I were back and forth whether or not to have it [genetic testing].”

All of the participants were asked to make the decision regarding genetic testing during a very difficult time. As they all demonstrated some feelings of ambivalence with both positive and negative feelings toward the decision to test or not to test, the APN helped guide them through this process. When the information about genetic testing was presented to these participants there was a great deal of discussion with the genetic counselors and the APN. The APN provided an environment conducive to shared reflection and understanding so that these participants could explore their feelings in an open and nonjudgmental environment. A major source of the ambivalence about whether or not to do the genetic testing in these families is the concern about the future implications of the tests.

Families struggled with the knowledge that if the results were positive, they or their loved ones could potentially die. When P3 was informed of her daughter’s positive genetic testing for Long QT Syndrome (LQTS) her daughter was hospitalized. She was prescribed daily medication and underwent the surgical placement of an internal defibrillator (ICD). After this process P3 stated, “How do I say to her ‘I’m afraid you

might die if something happens to you.’?” Although, these families struggled with the decision they also demonstrated positive feelings about knowing the results once they decided to have the testing done. P5 stated, “I could look at it [genetic testing results] as a negative thing that my kids have this, but I focus on the positive, that I’m glad of the medicine, I’m glad we were able to catch this.”

In summary, all of the participants experienced feelings of ambivalence of genetic testing. The participants and their family members had genetic testing for the LQTS gene performed but throughout the process expressed feelings of ambivalence. They expressed concerns about the decision-making process. They wanted the information the testing would give them but on the other hand they felt that their lives would be changed once this information was revealed.

**Family blame/withholding information.** The theme of blame of other family members was apparent in all interviews. When reviewing the data the theme of blame was specifically directed toward members of the family. The family members that have had other family members affected with SCD experienced feelings of blame. All participants found fault with other family members for their unwillingness to share medical information. In one participant it was clear to why the family member withheld medical information. In the remaining four participants it was unclear to the reason medical information was withheld from the participants.

Along with blame, feelings of withholding information of family members were noted. P3, expressed her feelings of blame and said, “So I guess I was a little upset, because after her brother died [half-brother of her daughter] I was saying to myself, well if her father would have just gone to the doctor. . . . I don’t know if they would have

found anything at that point, but you know, maybe he just should have taken better care of himself.” When the daughter’s father died suddenly, P3 became suspicious that there was possibly a familial disease that may be inherited. Since these deaths occurred within a year of each other, P3 initially had her daughter evaluated by her pediatrician. She was later referred to the Cardiogenetics Clinic for evaluation. P3 expressed these feelings after her husband and his family did not take any steps to evaluate what was happening to them. Because her husband’s family did not take any action after the death of two family members she had feelings of blame toward his family. P3 expressed this feeling of blame when she asked, “I just don’t understand how his [husband] family could think there is nothing wrong with their family after so many people died, how could people be so blind?”

Some family members’ feelings of blame started when they perceived the deceased family member’s inability to care for themselves. Others blamed family members for the failure to recognize the possibility of a potential genetic condition. P2 seemed to blame her daughter-in-law for the death of her son and grandson when she said,

She [daughter-in-law] told me of her son fainting four or five times, and how the last time he fainted it was the longest that he was out. And then she said, “But I don’t think that’s our side of the family.” And I was like, “Do you hear yourself?”

P2 was concerned that her family was not really looking at what was happening to the members of their family. She was angry that other family members let their pride get in the way of taking care of what they now know is a genetic LQTS mutation in this family. P2 had discussed with the APN that these feelings of blame had led her to communicate



less with her husband's family because she felt they let the family pride get in the way of caring for their other family members that may be at risk for SCD.

Feelings of blame may become very powerful in a family and may, unfortunately, lead to discontent with the sharing of medical information. P1 was concerned about her daughter's evaluation for SCD when the interprofessional team asked her for information regarding the medical history of relatives; her brother-in-law was known to have a cardiac issue. During this discussion P1 showed her frustration when she said, "If her uncle has information, he is not willing to give the information. And I won't get into it, but when his mother passed away, the inheritance has been an issue." When the APN had called P1's brother-in-law, with permission from the other member of the family, the APN explained that having his medical information would help his niece (P1's daughter) during this process of evaluating for her risk of SCD.

P1's brother-in-law was very pleasant on the telephone and after the call sent a follow-up e-mail to the APN. The e-mail included a legal document that had many restrictions and made it very difficult for the interprofessional team to access any information. The document was sent to the medical center's legal department and it was determined that the legal document that was sent could not be signed. The evaluation of P1's daughter continued despite the unwillingness for P1's brother-in-law to provide his medical information.

In summary, all the participants experienced blame of family members and withholding information among family. Some participants blamed family members for not being aware of the possibility of genetic conditions in their family. Other participants blamed the deceased members of their family for their inability to care for themselves.

These feelings of blame led to discontent when other members of the family are not willing to share medical information. The ability to share medical information in a family is crucial in understanding the genetic history of a family. This information may benefit these family members in terms of understanding the genetic conditions in a family. Some participants expressed the discontent of not sharing this information and it led to family discord, as well.

**Fear of death.** Fear is a common emotion that occurs when individuals have encountered external stimuli that release an intense emotional state (“Fear”, 2001). During the interview process participants expressed concerns or feelings about the fear of death of their children. This fear of potential death was expressed by P5, who said, “I got very scared. I have two lives here that depend on me and it came to a point of questioning myself, as a man, as a father.” After his wife’s death, P5 was dealing with the loss and at the same time doing everything he could to protect his children. P5 had two telephone discussions after the interview with the APN regarding the care of his children and how to overcome his fear and not become paralyzed by fear. Through the APN interactions, P5 became aware of the evaluation options and potential treatment options available to his children. This understanding was able to help P5 act on helping his children and not become paralyzed by fear. In telephone conversation after the interview, P5 stated “ I need to do whatever it takes so nothing bad happens to help my kids”.

The response to the fear of death was expressed in many different ways. P3 had stated, “How do I say to her—‘I’m afraid you might die if something happens to you’?” P3 is a very stoic mother who has helped her daughter get the proper evaluation for LQTS when others in her family had thought she was overreacting. In the discussions

with the APN, P3 explained that she was concerned about the treatment possibly failing her daughter. Her daughter was prescribed daily medication to prevent arrhythmias and had an ICD surgically placed to internally defibrillate a lethal arrhythmia. P3 was concerned about treatment failure, which could lead to her daughter's possible death.

During the interviews parents were encouraged to speak to their children about the fear of death because it appears to be of great concern for the parents of children with LQTS. P1 exposed her fears for the health of her adult daughter in this way:

I hope to live a long life and have peace of mind that knowing that hopefully my daughter will live past the age of 37. I'm scared for E [daughter] when she hits her 30s, because every year she gonna be like, Thank God I'm alive.

P1 discussed this fear of her daughter's death with the APN. The sudden loss of P1's husband had left her with many unanswered questions regarding her husband's death. She had attempted to understand why and how he died. This fear had initially driven her to have her daughter evaluated for the potential for SCD. P1 had further persisted for an evaluation when her daughter was having symptoms of palpitation. This fear had helped her express her concerns and led to the Cardiogenetics Clinic evaluation.

Although, other participants were able to openly discuss the fear of death, P4 found it difficult to see the term sudden cardiac death in print. P4 found it difficult to discuss the possibility of death. She found it so challenging that when she saw it written in a document she became very upset. This was explored in a telephone conversation the APN had with P4. The APN initiated a follow-up call and spoke about a letter that had been sent by the NIH research team to provide information regarding the NIH study. She said that the letter contained the words sudden cardiac death in the context of describing

“families that have experienced the loss of a family member from sudden cardiac death.”

P4 stated:

It doesn't pertain to us. . . . I was really upset about the letter because I just . . . felt like it was worded really poorly. And it was like a shock to me because they're talking to me about my child having died. . . . I know it can happen, but it was just worded so.

The APN discussed this information with the rest of the interprofessional team and changes were made to the document from this interaction. The team realized that the term death was difficult for this family to read, and this may not be the only family that had this concern. The term was changed to sudden cardiac episode, so it could be explained in more detail to families. The interaction of the APN and participant is not uncommon in the Cardiogenetics Clinic. The APN's role has evolved to being the leader of this interprofessional team and has assumed the major responsibility of evaluating the concerns of the families and discussing them with the interprofessional team. This process adds meaning to the interaction with the family member and interprofessional team. The concern of the term death being printed in a document may have elicited the similar feelings of fear in others but it was the interaction of the APN and participant that led to this the participant's relief of this fear and a positive change in a document that may now help others as well.

In summary, the findings of the themes of the lived experiences were focus on health, guilty feelings, and, ambivalence to genetic testing, family blame/information sharing, and the fear of death. These discussions were explored during the APN and

family member interaction. These interactions have revealed the many concerns families experience in this time of loss and potential loss.

## **Question 2: Experiences with the Cardiogenetics Clinic**

The second prompt that the family members were given during the interview was “Tell me the story of your experience with the Montefiore Cardiogenetics Clinic.” From this, the following themes emerged: fragmented care prior to attending the Cardiogenetics Clinic, feelings of being heard, mutual process and, meaningfulness.

**Fragmented care prior to attending the Cardiogenetics Clinic.** Fragmentation in healthcare delivery is defined by Shih, Davis, Schoenbaum, Gauthier, Nuzman and McCarthy (2008) as the systemic lack of coordination that spawns inefficient allocation of resources or harm to patients. Fragmentation adversely impacts quality, cost, and outcomes. Fragmented care is evident in participants’ descriptions of being evaluated by multiple professionals at different times and various locations. In three of the five interviews the participants reported the multiple steps they pursued after they were either referred to or sought more medical help on their own. P5 stated, “I don’t recall who initiated it [referral to the Cardiogenetics Clinic], in the hospital. A referral from the primary doctor? I just don’t recall.” P5 struggled to recall this information because his wife had undergone referrals from two different medical centers. During that time the couple was undergoing a marital separation. P5 had expressed these struggles to the APN when he had called to contact the Cardiogenetics Clinic.

Other participants expressed similar experiences. In P4’s interview, she recalled multiple visits to the pediatrician’s office. She felt she was not getting any answers when her son had multiple syncopal episodes. She had spoken to the pediatric office and

recalled, “a phone conversation and I said ‘But, I’m the mother.’ And I was like, ‘You’re talking about my kid.’ So I wasn’t very happy, so I started making some phone calls.” She recalled making multiple calls and going on the Internet to find out if anyone could help. P4 was able to share this story in greater detail during a telephone conversation with the APN. P4 expressed to the APN that she felt the other healthcare professionals did not understand how to evaluate her son. She became frustrated and concerned that the professionals were ignoring her concerns and not fully explaining what was happening to her son. P4 had said that she was referred to other professionals and the information was inconsistent.

The level of frustration in the fragmented care that P3 received was evident in her interview. P3 stated, “I sat in a room like this for 45 minutes before I said something to the nurses. . . . She told me, ‘Oh, Dr. S left in an emergency.’ . . . I took off the day from work to come here . . . but at least say something.” This mother had sought information on her own after her husband and his stepson died within two years. She was her daughter’s advocate for investigating the possibility of these two family members having postmortem genetic testing. This information helped her daughter get tested for the same gene mutation that led to her father’s SCD. P3 had stated in a telephone conversation that “It just didn’t sound right to me that two people like this can die suddenly without any reason.” P3 was frustrated at the fragmented care that she had received but had then taken the lead in finding a healthcare facility that could evaluate her daughter. She had investigated facilities with a comprehensive approach and found the Cardiogenetics Clinic through an Internet search.

In summary, three of five participants reported experiencing fragmented care prior to attending the Cardiogenetics Clinic. The participants expressed the fragmented care they received from many different healthcare professionals and facilities. This fragmentation led to confusion about their family members' illness. The discussion of these feelings led to awareness of their feelings of confusion and frustration. These experiences also led them to the further investigation for a comprehensive approach to their care.

**Feelings of being heard.** A sense of being heard or being understood was evident in the stories of the three of the five participants. They felt that they were in a place where their whole family could come to and be heard. When exploring this theme of being heard at the Cardiogenetics Clinic during the interviews, the participants expressed different perspectives. P5 voiced his gratitude saying; "I felt having all the information given to me by the team helped me." His wife had undergone several evaluations by two other medical centers and had received so much information that she did not act on it.

P3 expressed her feelings for the team approach in this way: "I think they did a really great job in just explaining to me what they thought could possibly be the cause of the sudden death of both her half-brother and father." During a telephone conversation, P3 said that she had always felt that there was a connection to these two sudden episodes and that her daughter may have inherited the condition.

P4 simply observed "After my friend said that she would connect me with E [the APN], everything seems to be going smoothly." P4 had undergone many fragmented visits with the pediatrician and wanted answers that she felt this professional could not offer. The APN has had six phone conversations and follow-up calls with P4, as well.

When this mother called to schedule a follow-up appointment she always asked if the APN would be there and the APN reassured her that she would be. This mother had expressed a connection, because she had made five telephone calls to other health professionals that did not know how to help her. In a telephone conversation she said that she “was relieved to hear someone on the other line that knew what I was talking about.” This participant expressed that she was heard and understood by the APN.

In summary, all the participants experienced feelings of being heard in the Cardiogenetics Clinic. The participants expressed feelings of being understood after their experiences with fragmented care. They described feelings of understanding the information that was presented by the interprofessional team members. The participants found the comprehensive approach to care beneficial for the members of their family.

**Meaningfulness.** Newman’s (1994) HEC theory defined meaningfulness as being the process of how an individual views his/her current situation and how it fits into his/her evolving pattern of interaction with that which is meaningful to the individual. During various interviews participants reflected on understanding and attempting to find meaning in the journey on which they had suddenly found themselves. P2 showed her appreciation of meaningfulness by saying: “I was glad when I knew about the LQTS, because I was thinking ‘What could cause them to die like this?’ And everyone giving their own opinion of what it could be-saying this, saying that. There’s some closure now.” This mother embarked on this journey with the help of her religious beliefs. When asked to explore this, she said, “He [her adult son] had accomplished his mission, and God must take him home now—he was ready to go, so that gave me reassurance.”



Meaningfulness was further expressed by P2 as she told the story of her deceased son and grandson. P2's son lived in Georgia and had a very strong religious belief. His mother was very proud of this and the fact that he was helpful to everyone he had met. Her son was a builder and would build homes in Georgia. P2 is a teacher in New York so she would visit her son during the school breaks before his sudden death. She had visited him a week before his sudden death and left with a feeling of happiness after her visit. It was the second week of January and they had packed up all the Christmas decorations. A week later P2 had received the call from a relative saying that her son was found on the floor unresponsive. His relative called emergency services and they instructed him to perform CPR and rushed him to the hospital where he was pronounced dead. After being notified of her son's death, P2 flew to Georgia she stated, "That was it [son's death] so it sort of prepared me, anything can happen in my life. I just prepare myself for anything, and the worst that can happen is death, so . . . " She appeared to reflect on these feelings in order to come to some meaning or understanding of her son's death.

P2 ended the interview with "it gives me some closure, knowing the cause of death, but there are times you are talking about it and become emotional, you remember certain things. A death like this any time you're talking, it triggers some memory, and I'm just going to feel the same way. It depends on the individual because people react to situations differently. " She repeated, "[death] sort of prepared me for anything that can happen in my life." During the interview she spoke of her strong faith: "Taking away a son like this without even having time to say goodbye. Only He [God] knows, and I am so glad." During this interview process P2 was able to reflect and find meaning in her personal experience of the death of her son and grandson. P2 and the APN had three

discussions about her loss during the interview and clinic process. P2 reflected on moments of her son's life that had added to meaning for her and others that had known him. P2 stated that she found meaning in moments of when the APN listened and held her hand when she was speaking about her son.

P3, had a different experience in finding meaningfulness. P3 explored her experience with her young daughter with LQTS who had undergone evaluation and treatment. She seemed to find meaning in helping others understand the circumstances of family members that have experienced a SCD of a family member. P3 stated:

You can wait for the parent to call, but I think you know maybe just for my family, I won't speak for all people of color, but I think everyone should know that we all deserve the kindness and understanding my family was given. I just don't think it happens, and it needs to, so others can be helped to prevent bad things from happening.

P3's observation was made during a time when she was researching her daughter's condition. When her daughter was evaluated at the Cardiogenetics Clinic and it determined that she had a concerning ECG, P3's suspicion that something was wrong was validated. She appeared to be grateful for the information that has helped her daughter. Her daughter was immediately admitted to the intensive care unit when she arrived for treatment based on her very abnormal ECG. She was in imminent danger of a possibly having a lethal arrhythmia that could have stopped her heart.

P4 had a similar experience when she spoke of her adopted son. She found meaningfulness in being informed of her son's condition and knowing the treatment options. She said,

I guess it's one of these things that you have to take it from the person, like you said, some people want to know more and some people want to know less. Even within the same family. And then some children will do their own research and my son's kind of like whatever, at this point anyway.

P4 had always had questions about her son's condition and was instrumental in supporting others with similar conditions. She had found meaning in becoming involved in support groups for parents that have children with the same condition. P4 had stated she had found meaning in helping others access care at the Cardiogenetics Clinic because that process was helpful to her understanding her son's diagnosis of LQTS and what it means to him.

For P5, meaning was the idea that "once again I just look at it like things happen for a reason. I never would have found out [the diagnosis] and I always heard about stories about kids participating in sports and all of a sudden they just collapse and they don't know what happened." He appeared to be grateful that his children are being treated, although he was still mourning the loss of his wife. He finds meaning in his wife's death because their children were diagnosed and treated for LQTS, which they may have not known about if she did not die. P5 refers to this discussion and as difficult as it was to process this loss, at least their children were treated for LQTS. P5 had stated to the APN that his wife would have also found meaning and comfort in knowing that her children were treated for the same genetic mutation (LQTS) that had killed her so suddenly.

In summary, all the participants experienced feelings of meaningfulness. The participants reflected on attempts to find meaning in this personal journey of the loss of a

family member to SCD. The participants also had experiences of understanding the process of illness and the possibility of helping other members of their family. This process of being aware of the meaningfulness of this experience also led to their evolving pattern of health as expanding consciousness.

**Mutual process.** The theme of mutual process between the APN and the participants was evident in all five interviews. In Newman's (1994) HEC theory, mutual process is identified as an integral connection between the human field and the environment. This interaction is related to the APN suspending judgment and being present in the moment during the interview.

During the process that the APN suspends judgment the participants have the ability to be present in the moment and share dialogue with the participants to explore what is meaningful. This interaction is illustrated as mutual process. An example of this experience of mutual process between the APN and P1 is expressed by P1's statement that she felt "peace of mind knowing that I'm healthy and my daughter is healthy." P1 made this statement after all of the interactions she had with the interprofessional team members, especially the APN. P1 expressed these feelings upon having awareness that the results of genetic testing showed that her daughter was not at risk for SCD. P1 said that she valued all of the discussions and the telephone conversations she had with the APN, which helped her process all the information she had known about her husband's death. P1 stated that it not only helped her process the past but also all the new information that she was given about caring for her daughter, who is now 21 years old. P1 has been very involved with her daughter's evaluation for SCD. Her daughter, even as

an adult, has always asked her mother to accompany her to the Cardiogenetics Clinic for support, understanding, and the ability to process all of the information presented to her.

Another example of mutual process was evident between the APN and P2. The social worker and psychiatrist had spoken to P2 about the death of her son and had left the room. The APN entered the room to discuss any other concerns, P2 began to sob. The APN sat with her and just listened to her speaking about her son. When the mother was ready, the APN asked if she could share this information with the other team members. The mother smiled and said that it would be helpful if she could speak to the psychiatrist again, because she now felt ready to get some help with her feelings. When the APN discussed this interaction with the team, they returned to the room and spoke to P2, helping her to arrange visits to a family counselor. In this interaction of mutual process with the APN, P2 was able to express feelings of sadness and memories of her son.

A different example of a participant's interaction in mutual process was identified in P3's interview when she explored her process of identifying the need for the health professionals' awareness of cultural sensitivity. P3's daughter was evaluated, hospitalized, and had surgery related to her diagnosis of LQTS. Throughout her journey she often identified hurt feelings and instances of prejudice and insensitivity related to her socioeconomic and intellectual status. She said, "I remember being in school and there are always studies that they do that show people of color are less inclined to seek medical assistance or psychological help until the very last moment. And so going through this process, it's just like that." P3's ability to share this discussion with the APN was helpful to her. P3 had stated that she had this experience during her daughter's hospitalization for LQTS, but it meant much more to her when she shared this interaction

with the APN because she felt it could make a difference in the care of other African-Americans that come to the Cardiogenetics Clinic.

One participant's awareness of mutual process came while exploring feelings of connectedness with others. In the interview with P4, this mother explained how she felt. She said, "I feel so connected with the national organization. If telling my story can help others I am grateful." Because she had the experience of wanting more information she, in fact, had become an advocate for families owning external defibrillators, especially during sporting events. When the interprofessional team recommended purchasing the external defibrillator, because of her son's diagnosis of LQTS, she was very receptive. At the time, she said, "Well, to me, I feel it's like better safe than sorry. It's something [the external defibrillator] that is useful for anyone." During the interactions with the APN, P4 expressed these feelings of connectedness through the experience of mutual process.

P5 expressed his experience in mutual process when he said, "I'm learning through my kids. I'm learning through myself. I'm looking at the bigger picture." His journey had started with his wife's sudden death and then the discovery that she had the genetic mutation for LQTS. Once he found out that both children had the same genetic mutation for LQTS, his journey took another turn. He said "I could look at this as being negative [the fact that his children's genetic tests were positive], but my focus is positive, because I'm glad there are medicines and other things we can do." The ability for the participants to express these feelings with the APN, who suspends judgment and respectfully listens, is an important shared experience to discover what is meaningful with participants. The interactions of the APN and the participants in mutual process are unique with each participant.

Mutual process was explored also, within the interprofessional team. The participants received care in a comprehensive Cardiogenetics Clinic approach that is a unique health care delivery model. These families have also expressed the importance of the interaction in which they receive and evaluate the information provided by the interprofessional team.

P4 expressed the feelings she had for the encounters with the interprofessional team. She said, “I feel like we know something’s there, and someone is looking into it. That is some kind of comfort.” P4 took comfort in the interactions she had with the interprofessional team. She had spoken to the APN about the connected feelings she had with the team member’s. P4 said that she appreciated speaking with all the members of the team. These discussions helped her understand her son’s treatment options and the best outcomes for his care. P4 appreciated being informed and said she had taken comfort in processing all the information.

Taking comfort in the mutual process with members of the interprofessional team is evident in P2’s statement of her son’s death from LQTS, “I always say an ounce of prevention is better than a pound of cure, if you can know you can help—it’s better to know.” Although P2 had lost her adult son, she wanted to do anything she could to help her grandchildren. She had spoken, in depth, with the APN and interprofessional team about the SCD of her son and grandson. She had many interactions with the interprofessional team that had led her to understanding that she could help her granddaughter. She said that she was willing to help others so they could be aware and be informed of SCD and how to get help. P2 was able to process the loss she had felt and because of her ability to interact with the interprofessional team expanded her own

consciousness. P2 had participated in multiple research interviews so that she could help others in their quest for understanding of this genetic disease.

P5 had expressed his interactions with the interprofessional team:

So once I found out that the kids have it [genetic mutation responsible for LQTS], it was very hard, it was very hard to take in. So I try to look at it in the positive side. I'm very grateful that I did find out, that they were able to catch it, and did the testing, and I'm able to help them at a very early age with the medicine and stuff.

P5 struggled with the loss of his wife and was grateful in having this information so that it may help his children. This father's interaction with the APN helped in this process. He also called the APN and discussed questions and concerns about his children. He scheduled follow-up appointments because he knows this is an important part of his children's care.

## **Summary**

The participants appeared to be eager to participate in this study. They had participated in the NIH study and had met the APN researcher. The establishment of the connected relationship through mutual process of the family member and APN appeared to be significant in the exploration of the meaningful experiences these families have with SCD and the Cardiogenetics Clinic.

The APN researcher's ability to provide a nonjudgmental, safe environment and ability to presence with the participant was essential to this interview process. The APN also utilized telephone conversations, field notes after the conclusion of the interview, and specific medical records of the families in this study. The APN and participant



interaction had led to the exploration of multiple themes. The themes of the lived experiences explored the focus on health, guilty feelings, ambivalence about genetic testing, family blame and information sharing, and the fear of death.

When exploring the question of the experiences of attending the Cardiogenetics Clinic multiple themes emerged such as the participant's experience of fragmented care prior to attending the Cardiogenetics Clinic and their feelings of being heard, the mutual process, and meaningfulness. The participants explored these experiences with the APN and what emerged from this data was a new model of comprehensive care and a deeper understanding of the families that have experienced SCD. This new model of comprehensive care appears to have made a positive impact on these families. The positive impact of this APN led model of care has led to a deeper understanding of the families' experiences with SCD.

## **Chapter 5: Discussion**

### **Introduction**

Gaining insight into how the Cardiogenetics Clinic influenced the families who attend the clinic allows the interprofessional team members the opportunity to better understand the needs and experiences of family members dealing with sudden cardiac death (SCD). This study provides this insight and offers other centers methods of recreating this model in order to address the needs of these families.

Chapter 5 presents the implications and recommendations from the findings of the research study conducted to explore the lived experiences of families that have experienced SCD. To date there has been no research addressing the lived experiences of individuals that have experienced SCD of a family member and the nurse's interaction while participating in a specialized Cardiogenetics Clinic. Although, prior and current research has addressed certain aspects of the design (Ingles, Lind, Phongsavan, & Semsarian, 2008) of the interprofessional approach to cardiac care, none of this research has evaluated the role of the Advanced Practice Nurse (APN) in this unique model of care.

The theoretical framework of the study was Newman's Health as Expanding Consciousness (HEC), which was used to explore the interaction between the APN and family member. This theory has been explored in the context of chronic illness (Falkenstern, Gueldner, & Newman, 2009). The APN researcher focused on the storytelling process of these unstructured interviews. She provided an atmosphere of

comfort, safety, and suspension of judgment. This process supported the APN's and participants' evolving pattern of expanding consciousness. The result of this process led to the integration of nursing theory, practice and research, which is described by Newman (2008) as nursing praxis. The data revealed that when the APN utilizes this nursing praxis, the client's perceive a more comprehensive and integrated model of health care delivery is elevated.

The exploration of the lived experiences of families that have experienced SCD revealed several themes such as focus on health, guilty feelings, ambivalence and genetic testing, family blame and withholding information and fear of death. When these family members were asked to explore their experiences with the Cardiogenetics Clinic the themes that were revealed included fragmented care prior to attending the Cardiogenetics Clinic, feelings of being heard, mutual process, and meaningfulness. These themes provide the family members and interprofessional team members with a greater understanding of the process of SCD, their lives after this loss, and the experiences of going through genetic testing.

This study revealed the integral role of the APN within the interprofessional model of care that focused on the Cardiogenetics Clinic. As the APN listened to each participant share their feelings regarding their experiences of SCD, in mutual process with each person listening, opening themselves to the experiences each one has had, and offering support and comfort, both the APN and participants transformed and expanded their consciousness. As the APN moved through the process with each participant, she connected with each family member and experienced SCD in a new way, one that offers the ability to feel the feelings of loss, ambivalence, focusing on health, guilt, blame, fear

of death, and, discovering the meaningfulness of SCD and its impact on families. This mutual process of listening and offering support and information is known as presencing and has the potential to transform the APN and each participant to a new level of being and understanding as they supported each other through the process of genetic testing and follow-up care.

The results of this study answered the research questions and demonstrated the potential for APNs to transform the process of healthcare delivery. The research questions that guided the study were (a) What is the lived experience of families who have experienced the SCD of a family member? and (b) What is the meaning of the evolving pattern of the APN and participant's mutual process that facilitates HEC in families who have experienced SCD? The APN interviewed the participants both in person and on the phone. As the interviews were ongoing, the APN was part of the process of the participants expanding their consciousness to gain a deeper understanding of their feelings surrounding SCD and genetic testing while, at the same time, the APN grew to understand a new model of care for these clients.

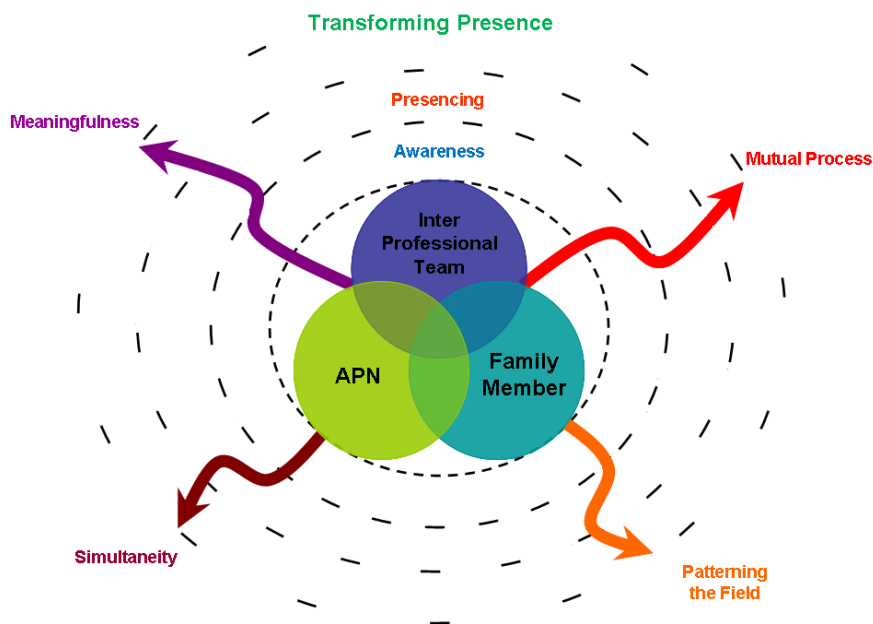
This process evolved into a nurse-led model of health care delivery, which supports the Institute of Medicine recommendations in *The Future of Nursing: Leading Change, Advancing Health* (CIOM, 2011) recommendations for nurses to take an active role in healthcare leadership. During the meaningful interactions experienced by the participants, APN, and interprofessional team members, through conscious awareness, presencing, and mutual process, a new framework evolved for APN practice.

## **Implications**

The experiences and interaction among the participants of this study led to the transformation of the participants, APN, interprofessional team members, and the development of a nurse-led model of healthcare along with a new framework of nursing praxis. The results of this study may impact health care for families who experienced SCD and potentially influence all families who experience death as a result of chronic illness. Additionally, these findings will change advanced practice nursing care and the interprofessional model of care for the future.

The APN recruited participants for this study during telephone conversations. This interaction was the first development of a sense of connectedness that was felt by the APN. The conversations the APN experienced were open and relaxed discussions of the study and the lives with the participants who agreed to participate in the study. Conscious awareness of what was meaningful became the theme during the interviews between the APN and participants. During the interactions in the interview process the APN attempted to provide a nonthreatening environment, suspend judgment, be fully present, and feel a connection with the participant. Through the process of journaling before and after the interviews, the APN was able to document these experiences. There were feelings of “openness” that the APN documented and “awareness” that was felt by both the APN and participant. At the end of the interview, both APN and participant experienced an expanding consciousness, which was revealed by the feelings of awareness and connectedness. The end of the interview felt like a continuation of a meaningful experience for the APN and participant.

Prior to this study being implemented, the Cardiogenetics Clinic had a traditional linear clinic process, as described in Figure 3.1. The original model of this interprofessional model of care was not representative of the process that evolved as a result of the interactions between the clients and interprofessional team members within the experiences of the study. The initial step-by-step process of the Cardiogenetics Clinic did not capture the depth and meaningfulness of the interactions with the family members, APN, and interprofessional team members that this new model provides for all participants. The process of interaction of the APN, interprofessional team, and the participants having awareness that simultaneously expands to presencing then is further expressed as a transformative process that has led to a new framework for a model that provides an integrated delivery of comprehensive care as illustrated in Figure 5.1.



*Figure 5.1.* Model for Integrated Delivery of Comprehensive Care.

Within this new model of integrated delivery of comprehensive care there are several concepts that influence this process of interaction among participants. As the APN, interprofessional team, and participant interact through the process of awareness,

presencing, and transforming presence, all three express meaningfulness of the process, evolving mutual process, patterning the field, and the simultaneity of the process. The term of meaningfulness refers to the unique experience in which the participant finds meaning (Newman, 2008). Newman (1994) has defined mutual process as the interaction between the human field and the environment. The term patterning is defined by Rogers (1970) as “a dynamic process. The continuous change that marks man and his environment is expressed in the continuing emergence of new patterns in man and environment” (p. 63). The process of simultaneity describes the unitary nature of care.

Parse (1991) described the simultaneity paradigm in her Theory of Human Becoming. She explained that: “in the simultaneity paradigm, human wholeness is a patterned configuration, not the sum of particulate attributes. There is no body-mind-spirit triad but rather a human being recognized through patterns in mutual process with the universe” (p. 35). Parse’s theory built on Rogers’ (1970) Science of Unitary Human Beings (SUHB) description of simultaneity. Parse (1991) builds on the paradigm by utilizing the tenets of existential-phenomenological thought. This deeper and more meaningful paradigm is an essential process for the APN, interprofessional team members and family member’s to become engaged in a transformative healing relationship

All phases of the transformative relationship include the APN, interprofessional team members, and participant, who are independent yet interconnected. The evolving relationship is represented by the three concentric expanding circles of awareness, presencing, and transforming presence in Figure 5.1.

The initial phase is the process of conscious awareness. Conscious awareness is the acknowledgement of an individual's physical and emotional surrounding environment. Within the study, as the APN and family member entered into the process of describing their lived experiences, both the APN and each family member became more aware of their physical and emotional environment. The APN through open dialogue with the clients was able to extend her awareness of the families' environment and gain a better understanding of their experiences. During these interactions both the APN and family member were more aware of their interactions, feelings, and experiences as they interacted with their environment. By providing descriptions of what they have experienced in losing their loved one or regarding the genetic testing process, the APN was able to become more aware of what this meant to the patients and families and how the health care process interacted with and affected them.

The APN reports and explains this expanding conscious awareness of the patients and families to the interprofessional team. Through providing the team with a more comprehensive and personal view of what the families are experiencing the APN helps promote expanding conscious awareness to all team members. This in turn helps all members have a more open and understanding interaction with the patients and their families, who are more deeply heard and understood. When all three members of this interaction are aware of each other and their surroundings, awareness of the moment evolves.

The process of conscious awareness expands into the process of presencing. Newman (2008) stated that: "being fully present is essential to a transforming relationship" (p. 53). In this phase the APN, interprofessional team, and participant



practice the suspension of judgment and interact with each other's environment by engaging in dialogue. As the APN becomes more aware of the environment in conscious awareness, she is now able to take this process to the next step of suspending her ideas, judgments, and preconceived notions, so that she can open herself up to the families' ideas, feelings, judgments or notions regarding the death experience and the process of genetic testing. By allowing oneself to recognize one's own judgments a person can strive to suspend those judgments in order to gain a deeper and more accurate understanding of other's ideas, feelings, or judgments. In achieving this, the person-to-person interaction is allowed to emerge in an open, nonthreatening environment where one feels safe discussing one's experiences and how one truly feels. As the APN and family member approach each other in this mode of presencing, their dialogue is open and honest, thus allowing them to gain a deeper understanding of one another and their experiences.

The APN also works with the interprofessional team to help them open themselves up to this process. Through helping them to suspend their own judgments regarding the genetic testing process, the APN can help them to understand the impact of this process on the families and the feelings the families may have, positive or negative, regarding the process. When the interprofessional team members are able to look at these feelings and experiences with an open and nonjudgmental environment, they become more aware of each person's surroundings, experiences, and feelings to move the process forward for the patients/families and themselves. This helps move all members to the next phase of transforming prescence.

Newman (2008) stated that transforming presence “is becoming one with the client. This involves letting go of external time and the constraints it imposes on nursing tasks. One must let go and be fully present in the moment” (p. 56). In this phase the APN is fully present with the family member and their experiences. The APN is not concerned with time constraints while interacting with the family. She is able to be fully present with the family and allows this interaction to be her primary concern. Through this process the family feels the attention given to them by the APN and feels valued and understood. The connection between the APN and client promotes more open and honest dialogue as well as trust and feelings of oneness among the participants. The APN also helps each team member focus on the patient and family during their interactions and discussions. She emphasizes the importance of the team members tuning out all other obligations, time constraints, and concerns so that when they are interacting with the clients, each client is able to feel that the members are actually presencing with them. This also helps to build trust among the client and the entire teams, helping the client feel respected, heard, and understood. This in turn allows each visit to help the families transform their experiences and themselves as they move through the genetic testing process, to expand their consciousness to understand where they have been in their experiences, to become more aware of their feelings regarding the process and what has occurred, to have greater understanding of what has occurred, and to move on in their lives with this awareness and understanding. For the APN and interprofessional team members the transformation process allows them to recognize what their experience with the family has meant to them and how they can gain a better connection with their clients.

The transformative experience encourages them to incorporate this new understanding of the families lived experiences into their daily practice.

During the phases of conscious awareness, presencing, and transforming presence the APN, interprofessional team, and participant are continuously experiencing expanding interactions through the process of meaningfulness, evolving mutual process, patterning the field, and simultaneity. During these interactions the APN, interprofessional team, and participant express meaningfulness of their experiences.

The conscious awareness of what is meaningful to each individual interacting among themselves expresses the evolving mutual process. Newman (1994) identified mutual process as the process of the human field and the environment. As the participant, APN and each team member interact with one another (human field) these experiences (environment) promote growth among each member of the interaction (mutual process). All interactions with each participant are unique and occur in mutual process in the progression through each of the phases.

While interacting in mutual process, the APN, interprofessional team, and client also experience consciousness expansion in patterning the field. Newman (1994) described the process of patterning as occurring “in the interpenetration of human energy fields as transformation takes place. The interference pattern of interacting waves forms a new pattern of the whole” (p. 72). Patterning the field refers to evolving energy fields of the APN, interprofessional team, and participant, which help them each expand consciousness in a new pattern of the whole. During the interaction with one another, the family members, APN, and interprofessional team members develop new patterns or ways of interacting with each other and the environment. These new patterns of

interaction incorporate what they have experienced through their mutual interactions, awareness of one another and their personal experiences. A transformation occurs as new patterns of being and interacting with the environment occur. The participants may experience a new energy field that incorporates these interactions that are occurring which may influence future interactions. The APN and interprofessional team members also experience a new person-environment interaction as a result of this transformative process.

This new framework of care can be applied to nursing praxis in developing future health care delivery systems. This may help transform current health care systems to new models of care that help address the Institute of Medicine's (CIOM, 2011) call for nursing-led models of care in the future of the health care. Every health care interaction is a process, within this model of care; the APN helps connect the client, interprofessional, and health care system to one another. The APN is at the center of this process and encourages these interactions of the patient and interprofessional team to allow movement through the process of illness and health to gain a new understanding of one's health and well being.

The APN's role (Appendix B) is integral to the structure and function of the Cardiogenetics Clinic. Additionally, the APN provides support for communication with the families of the Cardiogenetics Clinic as they move through the process of discovering their risk for SCD and possible treatment options. The research findings have explicated the role of the APN in this process. The APN, in the process of conducting the study, experienced conscious awareness and expanding consciousness. The process included the interactions in participant recruitment, the interview process, telephone conversations and

journaling. The APN is an integral part in the development of the Cardiogenetics Clinic. During the initial 2-year phase of the Cardiogenetics Clinic development a linear process had emerged (Figure 3.1). However, it was in the process of this study that the APN experienced conscious awareness that led to a new understanding of the role and function of the APN within this model of care.

Through the exploration and interaction of the APN and the participants, the findings revealed an evolving, multidimensional awareness of the mutual process between the APN and participants. In this new model (Figure 5.1) the APN, participant, and the interprofessional team members are in the center, with an evolving dialogue between the two that promotes the awareness of mutual process, which may lead to a transforming healing relationship. It was in this process of this study that the APN experienced conscious awareness that led to a new understanding of the role and function of the APN within this model of care. This new role for the APN expands beyond the traditional view of the APN's role in the Cardiogenetics Clinic environment. Within the new role, the APN interacted with participants in mutual process and this meaningful experience between the APN and participant evolved into expanding consciousness for both. Once APNs have the ability to become aware and fully present in the moment within their environment, they may be able to provide a nonthreatening environment, attempt to suspend judgment, and be fully present with the client's for whom they care for and may enable the APN to provide holistic, therapeutic care to the family members. Additionally, the APN brings a deeper understanding and awareness of the personal experiences of the participants to the interprofessional team members. This holistic process is beneficial to family, APN, and team members.

Several themes arose through discussion of lived experiences that show that the process of expanding consciousness has proven beneficial to the family members' experiences at the Cardiogenetics Clinic. The initial themes associated with lived experiences were guilty feelings, anxiety about genetic testing, family blame, and fear of death. Through the process of reflective dialogue themes emerged that showed that experiences at the Cardiogenetics Clinic had transformed into feelings of relief at the clinic's comprehensive approach, the importance of understanding the process, the meaningfulness of the process, the concept of mutual process, and the role of the APN within this process.

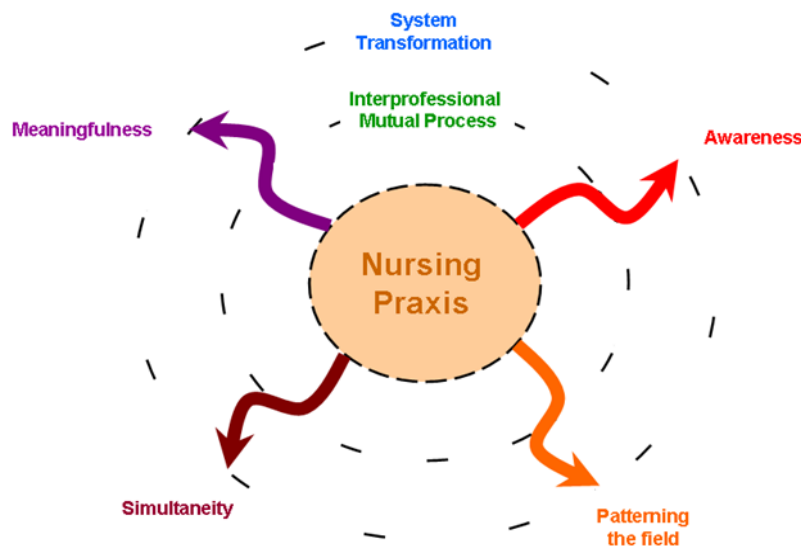
These research findings suggest conscious awareness through reflective dialogue facilitates transformative healing relationships. This awareness has changed how the APN sees her role as a coordinator that manages the clinic setting to a holistic practitioner in mutual process with the interprofessional team and family members of the Cardiogenetics Clinic. The APN may have been interacting in a holistic manner prior to this study but it is the conscious awareness of this process that has led to a deeper understanding of the experience of expanding consciousness and meaningful interactions.

The emergence of this data through the mutual process of the family member and APN is evidence of the transformation that occurred during this interaction. This may have major implications for nursing practice. As was evident in the shortcomings of the linear process that the family member and APN had practiced prior to this study, the transformation of the awareness that led to the nonlinear interaction of the family member, APN, and the interprofessional team has many benefits to practice. The family members, in mutual process experienced an expansion of consciousness. This process

explored the meaningfulness of difficult times such as this in these families' lives. The APN was able to gain an understanding of the families' experiences through their interactions during the interview and phone conversations. Their interaction has enhanced the role of the APN and improved the ability of the APN to help the families' process their experiences and the team members to enhance their practice.

The process has transformed the APN in her role and as an individual. Through the practice of suspending judgment and providing a supportive environment the APN's interaction and mutual process with the family members led to a transformation through understanding the meaningfulness of the families' journeys. The journal notes that the APN kept throughout the interview process document the self-reflections that were part of the APN's personal transformation. This is consistent with Picard's (2002) observation that "this self/family reflection is part of nursing praxis, since what transforms self, transforms practice" (p. 249).

The concepts of patterning and presencing offer a foundation for the integration of nursing theory, practice, and research. This integration is also known as nursing praxis according to Newman (2008). The implications of this study have come from nursing praxis and explore the following: what is meaningful, awareness of mutual process, knowingly patterning the field, and the simultaneity paradigm. This interaction is meaningful not only to the family member and the nurse but also the interprofessional team that is involved with the families' care. The transformation of linear care to nonlinear care had occurred during this research study. The evolution of a new model for interprofessional delivery of health care may be described as a systems transformation (Figure 5.2).



*Figure 5.2.* Framework for Transformative Nursing Praxis.

The transformation from linear to nonlinear process involved not only the family members but also the APN and the members of the interprofessional team. It is from this transformation within the interprofessional approach to care that the APN has taken an active role in health care and leadership. This active leadership quality in the APN role is consistent with Institute of Medicine recommendations in *The Future of Nursing: Leading Change, Advancing Health* (CIOM, 2011). In addition to the leadership role, the APN has achieved nursing praxis. Through the reflective dialogue centering on the meaningfulness of these families' pattern of relationships with the environment, the APN and participants have experienced expanding consciousness. Future implications to practice include the education of healthcare professionals in this new model of health care delivery that may apply to many specialty care areas in medical center settings.



A future implication this study encourages is the promotion of research in the Framework for Transformative Nursing Praxis and lived experiences of families in other interprofessional clinic settings. The explorations of families in the health care settings reveal rich data that not only encourage better health care outcomes but also the expanding consciousness of the participant and APN within an interprofessional setting.

### **Limitations**

There were several limitations in this study. One limitation was the small sample size of the families that experienced SCD. Due to the unique nature of this interprofessional Cardiogenetics Clinic, the once-a-month clinic meeting, and referral difficulties, many families are not aware that such a clinic exists. This was evident in the data retrieved from the study in what was described as the disconnected services experienced by these families. In this specialty setting the uniqueness of this clinic setting also limits access to these families. The only other attempts to contact these families are by telephone. Telephone access becomes challenging because of the unwillingness of participants to return calls and contact numbers changing frequently.

Other limitations were that the research was conducted in only one medical center and with family members who have experienced the impact of only one diagnosis. Conducting this study at multiple sites could add to further understanding of the lived experiences of these families. Encouraging other medical centers to explore the lived experiences of families that have experienced the SCD of a family member would prove beneficial to the families and interprofessional teams.

The role of the APN as researcher may be a limitation to the study, because only the perceptions of the APN are presented in this process. There may be bias from the

researcher view and clinical standpoint. There may, however, be bias because the APN had a professional relationship with the families of the Cardiogenetics Clinic. This may also be viewed as a benefit to the development of the mutual process that occurred.

## **Recommendations**

Recommendations for future study include raising conscious awareness of patients, other APNs, and the interprofessional team members. There is a need for more interviews of families that have experienced SCD. Because every medical center seeks accreditation from the Joint Commission Alliance, one of the major standards of care evaluated is patient satisfaction. So, there is a need to evaluate to patient satisfaction within the interprofessional health care delivery setting of the Cardiogenetics Clinic.

The first recommendation, raising the conscious awareness of patients through replication of this study, may provide further understanding in various contexts. The exploration, through quantitative or mixed-method studies, of the lived experiences of patients with similar genetic conditions may further describe their experiences and expand our understanding of these experiences and the needs of these patients. Interviewing the children of these families could also provide more understanding of the experiences of these families during this tragic time in their lives. Additionally, expanding the research to include multicenter interviews would provide rich data for further understanding and analysis.

The second recommendation is to raise conscious awareness of other APNs in similar roles. In this process of raising conscious awareness, the APN would be able to recognize and understand their potential and the possibilities for reframing the process of this model of health care delivery and evolving a new pattern of advanced nursing

practice. The APN has the ability to interconnect research and practice. The interprofessional team has evolved within this process that has centered the APN as a leader. The APN may encourage other professionals in regard to this practice model by providing educational meetings for practitioners during continuing education settings. By promoting more research, education, and publications regarding this new model of care, APNs can take the lead in addressing the CIOM's (2011) call for newer models of care that are nursing led.

A discussion or presentation of this study during a nursing research setting or forum may be another way to disseminate the implications of nursing praxis. Recommendations for advocating for the role of the APN are implementing discussions in the nurse-patient partnership through the understanding of Newman's HEC. These discussions may be held in the clinical setting and/or nursing orientation of all new professionals. Sharing what is meaningful for families and APN might become part of daily practice. This invitation to attend to the individual's wholeness can lead to awareness and expanding consciousness of families and professionals.

The third recommendation is to raise conscious awareness of the interprofessional team members to recognize and experience the value of an integrated model for the delivery of healthcare. The participants in this study have experienced expanded conscious awareness in this integrated model of care. The data has revealed that they have experienced meaningfulness, mutual process, and being heard. This is not only beneficial to the patients but to the interprofessional team members as well. In future studies, the exploration of the experiences of the interprofessional team members would lead to a better understanding of the value of the experience of this integrated model of

health care delivery. Future clinics created based upon this model should evaluate its effectiveness by assessing variables such as patient satisfaction, anxiety levels, and quality of life both pre and post participation in this model of care. Use of a comparison group for patients participating in a traditional model of care would strengthen such a study. This type of study can better explore the positive impact this model of care may have. These studies can help promote this new model of care and help reemphasize the importance of the APN's role.

As for future theoretical study, exploring this nurse-patient relationship with Dr. Elizabeth Barrett's (1989) Theory of Power as Knowing Participation in Change and Dr. Richard Cowling's (1997) Unitary Pattern Appreciation may evolve a deeper understanding of these families' lived experiences and further explore nursing praxis. A replication of this study using Barrett's and Cowling's theories in a mixed-method study may explore the nature of mutual process, evolving patterns and lead to expanding consciousness in both the APN and individual family member. In future research, another aspect of possible exploration could be made with Imogene King's (1981) open systems theory. Open systems theory helps promote the importance of nursing in helping to promote the interaction of the personal, interpersonal, and social systems. Exploring this theory in future research using both qualitative and quantitative methods, in the setting of an interprofessional Cardiogenetics Clinic may also help further the understanding of these models of care and how nursing promotes health within these systems and health care delivery.

The study has explicated the transformative nature of nursing praxis and is an important implication of this study. Future research can further explore nursing praxis in

any health care setting. The transformation from a traditional linear clinic model to a nonlinear process can be replicated in any health care setting.

## **Conclusions**

This study helped to demonstrate the integral role of APNs within an interprofessional model of care that focused on a Cardiogenetics Clinic. The results of this study highlighted the experiences of the families who have suffered death and loss in the setting of a genetic clinic aimed at identifying risks for other family members suffering SCD. Through exploring the lived experiences of families that have experienced the SCD of a family member, the role of the APN in this new model of care came into focus. Gaining insight into how the Cardiogenetics Clinic influenced the family members who experienced a SCD led to better understanding of the impact of their lived experiences.

The interaction these family members have had during this study has led to conscious awareness of their journey after they experienced SCD of a family member. The experiences described and the interactions the family members have had in this study has led to their expanding consciousness. The data showed that the families discussed the meaningfulness of this interaction with the APN and felt that they were heard. They were able to see growth and meaning within themselves through this expanding consciousness. They described this experience as a journey that allowed them to have a greater understanding of their own feelings, emotions, and experiences with losing a family member and how this has impacted their lives now and in the future. Finally, they were able to discuss their experiences with the genetic testing process and interprofessional approach to care. What these families expressed regarding their experiences with this

new model of care can be used to improve upon this model and enhance the quality of care provided to these families.

The results of the study not only answered the research questions but also demonstrated the potential for APNs to transform the process of the delivery of health care. The evidence in this study has supported the benefits to the family, the APN, and the interprofessional team in conscious and meaningful collaboration. This transformation from a linear to nonlinear process helped create a new model of care where the APN in mutual processes with the family members and interprofessional team members, helped each member experience transformation through understanding the meaningfulness of the families' journeys. The transforming nature of this process has encouraged family-centered care, strengthened interprofessional services, and provided seamless, continuous and coordinated care.

An important implication of the study is its support of the nurse-led model of health care delivery that contributes to advancing the recommendations of the CIOM (2011) to impact all areas of health care. As the CIOM stated, in order to promote quality of care in health care systems, nurses are in a unique position to create new models of care and promote change in practice among health care systems. The model described in the study demonstrates a new practice environment that focuses on the patient and family promotes quality of care that is patient-family centered and incorporates an interactive, interpersonal process that promotes patient's optimal health and well being. APNs are in a position to create this model of care within subspecialty clinics as well as infuse the principles of praxis and awareness of mutual processing within all health care visits, including primary care.

The data that was analyzed explored the profound influence the APN and interprofessional team members made. The implications that were derived from the data explored the interactions of the APN and participants through the process of conscious awareness, presencing and transforming presence. The data revealed the interactions of the participants and APN in mutual process and leading to expanding consciousness. This deep respect for the participant had a positive impact on the participant and APN. This study has profound implications for the future of health care delivery systems and nursing leadership. As demonstrated in the study, and APN-led model of care had a positive influence on families that experienced SCD which increased the participants' conscious awareness of their experiences, and led to their expanding consciousness. The APN-led model of comprehensive care has demonstrated the potential for improving the health care delivery system, patient satisfaction, and nursing praxis.

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## **Appendix A**

### **Montefiore Medical Center's Advancing Health and Enriching Lives**

**Montefiore**

## Advancing Health and Enriching Lives

The Strategic Plan for the Decade 2009–2019

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## I. New Beginnings

### Shaping the Future

We stand at a defining moment—a time when healthcare reform in the United States has entered the national dialogue and biomedical research holds great promise in treating and curing debilitating diseases. Our institution is at the beginning of an exciting new era. There has never been a better—or more pivotal—place to be than right here at Montefiore.

During this unique time, we took the opportunity to redefine Montefiore's mission, vision and values to chart a new path for success. This new Strategic Plan provides the institution with a fresh vision while renewing its commitment to its core values. The Plan also describes a series of Strategic and Organizational Goals, designed to elevate our institution to new heights of success. Through an inclusive process and careful review, we charted an exciting course of action that outlines our aspirations and serves as a guide for the coming decade.

The Plan's development began in early 2008, when Montefiore's newly appointed President and Chief Executive Officer, Steven M. Safyer, MD, with the support of David A. Tanner, Chairman of the Board of Trustees, set out to identify and define the institution's key strategic and organizational goals to position Montefiore for the future. The Strategic Plan builds on the institution's strengths and prepares Montefiore to adapt to rapidly changing regional and national environments.

At the heart of this plan is a bold, expansive vision for Montefiore, one designed to raise the institution's performance and stature as an academic medical center, to promote the development of specialty care programs and clinical Centers of Excellence, to improve quality of care and service to patients system-wide and to increase the impact of its community services.

### Exchanging Ideas, Defining Our Approach

Central to our planning process was an ongoing dialogue among key stakeholders from Montefiore, Albert Einstein College of Medicine (Einstein) and the community. A Strategic Planning Steering Committee, chaired by Dr. Safyer and comprised of administrative and clinical leaders from Montefiore and Einstein, with input from members of the Board of Trustees, provided insights and leadership critical to the development of the thoughtful and cogent plan. The Strategic Planning Steering Committee was supported by members of Montefiore's Planning Department and The Chartis Group, a healthcare management consulting firm. Dr. Safyer and the Strategic Planning Steering Committee created a series of objectives and benchmarks designed to:

- Present the institution's mission and vision
- Define the values that exemplify the Montefiore way
- Contextualize a changing healthcare environment and its implications
- Define the strategic and organizational goals needed to advance the vision
- Identify actions and methods needed to achieve the outlined goals
- Foster support for the mission and vision

### Setting the Course

The Strategic Planning Steering Committee began by conducting a comprehensive market analysis and needs assessment; it then reviewed and updated Montefiore's mission, vision and values statements. Committee members also reviewed a series of environmental assessments that analyzed both Montefiore's current competitive position within local and regional markets and emerging regional and national healthcare trends to evaluate how these trends might impact Montefiore. Diverse points of view were heard and incorporated. During the planning process, in-person interviews were conducted with more than 100 leaders both from within Montefiore and from the community.

Once the mission, vision and values statements were updated and the environmental assessments completed, the Committee discussed and crafted fresh strategic and organizational goals to guide the institution for the next 10 years. The final goals were developed based on the Strategic Planning Steering Committee's review and the advisory panels' recommendations.

Five advisory panels, with representation from key Montefiore and Einstein clinical and administrative leaders, vetted and refined the goals. These groups were asked to research and frame key issues, identifying the challenges and requirements to implement more specific strategies to achieve each of the goals. The advisory panels addressed five areas: academics, acute care, the integrated delivery system, Centers of Excellence and community service.

## II. Mission, Vision and Values

Since 1884, Montefiore has cared for the chronically ill and has made it a priority to improve the quality of life for underserved populations. This founding belief is the cornerstone of our mission, vision and values. Over the ensuing 125 years, Montefiore has grown into a 1,490-bed healthcare delivery system that treats over 90,000 inpatients and over 300,000 emergency room visitors per year. Forty percent of the patients admitted at Montefiore are Medicare patients; another 35% are on Medicaid.

Montefiore's mission is rooted in our enduring commitment to provide high-quality care to all patients—regardless of their backgrounds or health insurance. Our unique care delivery model combines innovation, dedication and academic and community partnerships. We seek to strengthen this model of care to advance health in our community and serve as an example to other urban healthcare systems.

## Mission

### Mission

**To heal, to teach, to discover and to advance the health of the communities we serve**

This four-part mission—to heal, to teach, to discover and to advance the health of the communities we serve—works because of our commitment to integrated clinical care and community service. We seek to educate the next generation of caregivers and create new knowledge through translational research. Montefiore is distinguished by its commitment to community service in combination with the clinical, teaching and research mission elements characteristic of leading academic medical centers.

## Vision

### Vision

**To be a premier academic medical center that transforms health and enriches lives**

To truly transform health at the community, regional and national levels, we must establish ourselves as a premier academic medical center and commit to raising Montefiore's performance and its ranking relative to other leading medical centers. Our partnership with Albert Einstein College of Medicine is essential to becoming an academic medical center that is a national destination.

## Values

### Values

**Humanity, Innovation, Teamwork, Diversity and Equity**

Montefiore has long prided itself on equity and compassion for all. Our values are rooted in our history as a leader in pioneering medical care, community health, social responsibility and innovative approaches to managing care. We foster a culture that is interdisciplinary, collaborative, respectful and rewarding, and we expect each member of the Montefiore team to uphold the following values, which support our mission and vision.



- **Humanity** – Our humanity reflects how we care for our patients and support the dignity and quality of life everyone deserves. It is a central aspect of our organization and of our team.
- **Innovation** – Inquiry and discovery keep us at the forefront of advanced medicine. They drive us to develop a high-quality, efficient system for the delivery of care.
- **Teamwork** – Inter- and multidisciplinary collaboration foster inquiry and discovery, improved quality and a thriving work environment.
- **Diversity** – We are committed to recruiting and retaining people from a broad variety of backgrounds and experiences to advance the organization and better meet the needs of our patients.
- **Equity** – Our patients and colleagues deserve to be treated in an unbiased manner at all times. We strive to ensure that all people have an equal opportunity to improve their health and we advocate for equal access to healthcare resources for all.

### III. A Changing Environment

Changes taking place across the United States directly impact our ability to provide the best medical care in the Bronx and beyond. The economic crisis of 2008–09 significantly strained federal, state and regional financial resources, and providers faced pressure for reimbursement from all payer sources. Obesity, diabetes, heart disease and asthma continue to challenge us. An increasing number of elderly patients require both acute and long-term care as they cope with chronic medical conditions. Such needs will demand that successful providers adjust their programs, services and care management capabilities for patients with these conditions.

#### The National Landscape

National economic fluctuations, changes to our healthcare system, and investments in medical education and technology all have an effect on what we do at Montefiore. When reviewing national trends, the Strategic Planning Steering Committee examined 10 key issues that affect healthcare providers now and that will affect them in the future. How we respond to these national issues will prove critical to our ability to advance our performance as a world-class academic medical center and as a model of integrated healthcare delivery.

#### Healthcare Reform

Healthcare reform will have a significant impact on the insurance industry and will affect how healthcare organizations provide care. Many people, including millions who were affected by the 2008–09 recession, are struggling to afford basic medical care. Montefiore has developed unique capabilities in caring for complex and chronically ill patients. Our ability to manage the care and improve the health status of patient populations burdened with high rates of chronic disease and poverty will set us apart from other academic medical centers.

### The Economic Crisis of 2008–09

Credit markets tightened as access to short- and long-term debt became limited and expensive. Federal and state governments continue to face severe funding constraints brought on by the economic crisis of 2008–09. These trends are occurring while leading healthcare organizations face pressure to spend capital at unprecedented rates to support clinical, operational and strategic objectives. Organizations continue to invest in procedural and specialty services with favorable reimbursement as a means of supporting underfunded clinical services.

### Cuts to Medical Education

As federal and state governments struggle with decreasing tax revenues and increasing program costs, they are considering dramatic reductions to healthcare and education programs. This economic environment has led to uncertainty about educational funding streams. Over the past two years, the Medicare Payment Advisory Commission (MedPAC) has called for cuts to Indirect Medical Education—a payment supplement Medicare gives to teaching hospitals to account for increased costs associated with educational programs. States have been cutting back on or eliminating graduate medical education funding dependent on state support. These cuts threaten the fragile financial position of many teaching hospitals and challenge clinical residency programs, posing a potential threat to patient care.

### National Institutes of Health Support

National Institutes of Health (NIH) research funding has decreased in recent years after unprecedented expansion through the late 1990s and early 2000s. The recent passage of the 2009 American Recovery and Reinvestment Act—also known as the Federal Economic Stimulus Package—provides a significant boost to research funding. NIH budgets are expected to grow by 34% over the next few years, from \$29 billion to \$39 billion annually. A large percentage of the \$10 billion increase is earmarked for clinical and translational research.

### Technological Advances

Healthcare organizations rely on the latest technology. Exciting new technologies such as genomics, proteomics, stem cell therapies, personalized medicine and telemedicine are fundamentally altering the detection, treatment and management of disease. Technologically advanced clinical treatment modalities are critical to the future of medicine; shifting demographics and increases in chronic disease already are increasing the need to implement more advanced care delivery capabilities. The number of patients age 65 and older is expected to double from 37 million in 2005 to 78 million in 2030. This trend will increase pressure on Medicare financing, but more important, it will drive a dramatic rise in healthcare utilization, particularly among people living with chronic disease.

#### Increased Outpatient Care

Technological advances have led to a continuing shift from inpatient to outpatient care. Innovative surgical and procedural techniques now allow large numbers of procedures to be performed in convenient outpatient settings, which are preferred by patients and physicians alike. Joint ventures between hospitals and physicians and physician-owned ventures continue to grow to meet the needs of this expanding market. This trend is changing the way hospitals deliver care and is forcing them to compete in new ways to maintain current patient volumes and attract new patients.

#### Consumer Demand and Transparency

Consumers today are armed with information about a range of treatments, from alternative to traditional, and are becoming more active partners in healthcare decision making. Greater access to information about quality and service and increased exposure to the financial implications of healthcare decisions have led to a greater focus on value. Healthcare providers need to be able to address consumers' questions and concerns. Providers also need to be prepared to respond to increased demands for transparency and consistency in clinical quality reporting and to support performance-based incentive programs created by commercial and governmental payers. These trends create heightened expectations for healthcare delivery systems and require providers to compete aggressively on multiple dimensions of performance, including quality of care, service and value. Consumer demand for outcome performance data will likely accelerate as more accurate and comparable data are made available and consumers expect to be actively involved in their health and well-being.

#### Workforce Issues

All segments of the healthcare system are experiencing staff shortages. The shortage of registered nurses (RNs) has been highly publicized over the past decade. While RN staffing is a key challenge within the healthcare workforce, RNs are by no means the only at-risk group. Shortages are projected for virtually all physician specialties over the next several years, particularly in the primary care specialties, including family practice, internal medicine and pediatrics. In addition, demand for technical and nonprofessional workers will outstrip the current and projected supply. While staff shortages vary in size and scope by market, they are driving increased costs and forcing providers to consider novel work arrangements, such as hiring hospitalists and intensivists. These arrangements are precipitating a change in traditional healthcare staffing models.

#### Challenges in Primary Care

Nationwide staffing challenges—among other factors—have stressed the primary care delivery system. Current projections suggest the demand for primary care physicians will increase 40% by 2020—requiring nearly 90,000 new physicians. Demand will rise even further under the new healthcare reform legislation as the number of physicians entering primary care specialties is expected to fall.



## Malpractice Reform

Medical malpractice premiums continue to rise substantially, placing significant pressure on healthcare providers and delivery systems. The cost of medical malpractice insurance started to increase in the early 2000s due to many high claims that were awarded, particularly in urban areas. At the same time, many insurers stopped offering malpractice coverage because of their low profit margins, making it more difficult to obtain coverage. Though premium increases may be slowing, medical malpractice reform is urgently needed to establish a ceiling on claims and reform the burdensome and costly legal processes.

In light of all of these trends:

- Health systems will need to quantify and report on the quality metrics and community service benefits they provide while continuing to prepare for governmental reform.
- Building operational scale will be important to enable health systems to develop clinical programs of regional and national stature while further spreading their fixed costs.
- Health systems will need to partner with other organizations to deliver care across the continuum.
- Academic medical centers will need to be more strategic and focused to secure clinical and translational research funding.
- Academic medical centers and teaching hospitals will have to find creative ways to fund teaching programs.

## The Regional Landscape

### New York State

New York State remains one of the most challenging financial and operational environments for hospitals and health systems. New York hospital margins tend to be 3% to 4% below national averages, driven by lower rates of reimbursement, high labor costs and state-related budget cuts. New York Medicaid continues to struggle with cost containment and is trying to shift more risk to providers to manage care.

The national payers have acquired all but one significant New York-based commercial payer, GHJ/HIP. Payer market consolidation increases payer negotiating strength and dilutes close local relationships that might have benefited Montefiore.

These statewide trends have several implications:

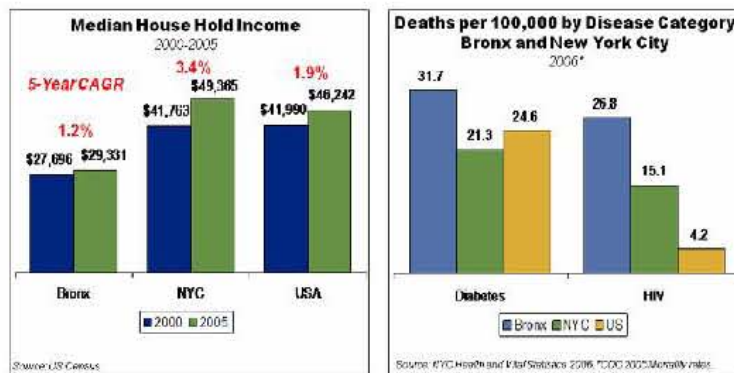
- Expanded ambulatory capabilities and facilities will be required to deliver and manage care across the continuum. The growth in ambulatory facilities will result in more diverse physician partnering arrangements.
- New models of cooperation and competition will emerge as the market consolidates. Providers will shift their focus from inpatient to outpatient care and from managing episodes of care to managing the long-term health status of defined patient populations over time.

- Competition will intensify for high-end specialty care cases; hospitals historically have focused on growing specific programs to generate needed margins.
- Hospitals will have to develop more robust specialty care programs to generate improved margins.

#### Our Bronx Community

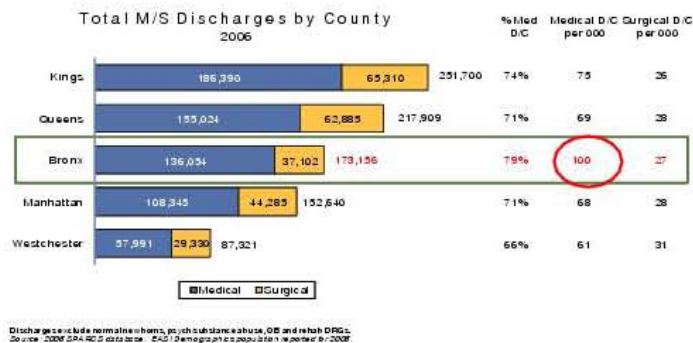
National trends manifest differently in various regional and local markets, including the Bronx.

A significant number of Bronx residents are challenged by poverty and lack of adequate access to care. Bronx residents also have a high prevalence of chronic illness, as well as more significant morbidity and mortality compared with New York State and national averages. The trends are highlighted in the graphics below.



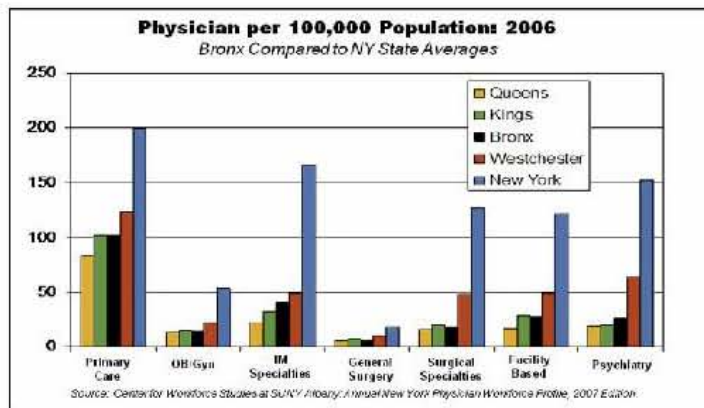
The higher disease incidence among Bronx residents has led to hospitalization rates that are significantly above New York City and national norms. As illustrated in the graphic below, the Bronx produced 100 medical discharges per thousand residents in 2006, a discharge rate 43% higher than the other New York City counties. Clearly, Montefiore and other Bronx hospitals must invest in prevention, disease management and community health and wellness programs.

Surgical discharge rates for Bronx residents are at or near the average for the five boroughs. Given the high profitability of surgical patients and the preponderance of medical patients in the Bronx, Montefiore should do everything it can to attract more surgical patients from the borough.



### The Workforce

The physician workforce characteristics in the Bronx are different from those in surrounding counties and in the United States. The Bronx has a much lower ratio of physicians per 100,000 people than Westchester County and Manhattan—especially in the surgical subspecialties.



The hospital landscape in New York is competitive and still evolving. New York State charged the Commission on Health Care Facilities in the 21st Century—a statewide initiative also known as the Berger Commission—with making recommendations to improve its healthcare delivery system and focusing on acute care resources. Many of the Commission's recommendations are being implemented, resulting in the closure or conversion of a number of acute care hospitals.

Montefiore can expect increased competition for secondary and select tertiary services from community hospitals. These hospitals are developing programs to attract more specialty care patients in an effort to increase their capabilities and case mix. In addition, highly skilled and well-funded multispecialty group practices will also compete to get more of the specialty referrals and surgeries.

## IV. A New Direction

### Strategic Goals

- 1. Advance our partnership with the Albert Einstein College of Medicine**
- 2. Create notable Centers of Excellence**
- 3. Build specialty care broadly**
- 4. Develop a seamless healthcare delivery system with superior access, quality, safety and patient satisfaction**
- 5. Maximize the impact of our community service**

#### Strategic Goals

The Strategic Planning Steering Committee agreed upon five strategic goals that are critical to the success of Montefiore. These goals touch upon all aspects of the delivery system and center on many of our external relationships that will help us grow, from the partnership with Einstein to our relationship with the Bronx community. Achieving these goals requires commitment and focus from each and every associate and member of our medical staff.

#### 1. Advance Our Partnership with Albert Einstein College of Medicine

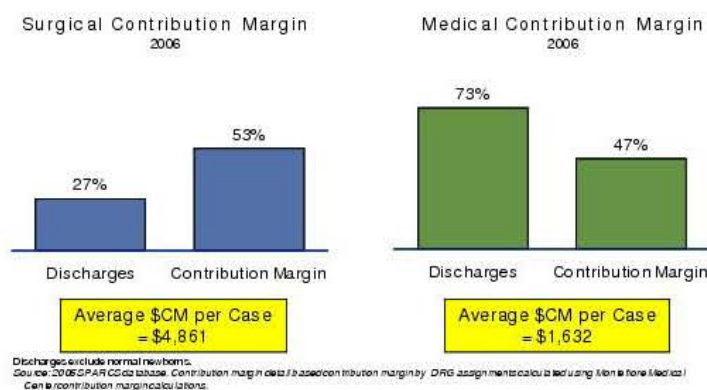
The first strategic goal focuses on our relationship with Albert Einstein College of Medicine (Einstein). Montefiore is the University Hospital and academic medical center for Einstein, one of the top-ranking medical schools in the country. The United States has only 129 academic medical centers—that is, accredited medical schools associated with a primary teaching affiliate hospital. Our relationship with Einstein is one of our key distinguishing assets. Montefiore, the second-largest teaching site in the United States, provides extensive clinical education and training opportunities, including clerkships for 750 Einstein medical students and graduate medical education for 1,000 residents and fellows. In addition, Montefiore recruits many attending physicians from its own residency programs.

When optimized and aligned, academic medical centers establish a “virtuous circle” where pioneering research attracts highly skilled, innovative clinicians who create new knowledge and breakthroughs in clinical care delivery. This in turn attracts the best students.



This “virtuous circle” creates powerful benefits for the hospital, the medical school, the affiliated physicians and ultimately the patients. Patients, physicians and students are drawn to places that provide cutting-edge care—which is available only where there is significant ongoing clinical and translational research.

Patients coming to academic medical centers often require more complex medical and surgical care, which, in turn, generates higher reimbursement and margins per patient compared with lower-margin, more routine cases. Improved margins enable the institution to reinvest in leading clinical programs, which reinforces the institution’s national standing.



The strong relationships between the leadership teams at Montefiore and Einstein have positioned us to become a premier academic medical center. The two institutions can achieve more together than either could achieve independently. We have an aligned clinical enterprise where the faculty practice and acute care operations are managed as a single, unified entity. We have strong foundations in research—Einstein is in the top 30 in NIH basic science research funding, and Montefiore receives more than \$40 million annually for clinical, translational and health science research.

To advance our partnership and achieve this strategic goal, Montefiore has outlined seven dimensions for its expanded relationship with Einstein:

1. Update the affiliation agreement: We need to update the Montefiore–Einstein affiliation agreement to define what we want to achieve together, how we intend to jointly operate and how we will fund our overlapping missions.
2. Develop a shared leadership model for notable Centers of Excellence: At the intersection of Montefiore’s clinical and Einstein’s research enterprises are the Centers of Excellence that span traditional academic department boundaries. We will define the shared leadership models and accountabilities for each notable Center to promote efficient operations and ensure success.



3. Co-recruit and co-support clinical leaders with Einstein: We will capitalize on the strength of our relationship with Einstein to attract clinical leaders of high stature and capability. Joint recruiting efforts and joint financial commitments for staffing, facilities and equipment will exemplify our shared commitment to recruiting the highest caliber of faculty and staff.
4. Partner with Einstein to grow clinical and translational research: We will develop a comprehensive, joint-research strategy to advance the standing of our research programs, particularly in clinical and translational research. This joint-research strategy will establish priorities for investigation and inquiry, as well as implement effective organizational and support structures to execute this strategy.
5. Enhance the quality of the educational programs: Strong research and cutting-edge clinical programs attract the best students and residents. Access to creative teaching methods and superior faculty helps cultivate skillful clinicians. We will develop novel teaching approaches to equip our physicians with the skills required to lead the next generation of clinicians and researchers.
6. Establish co-branding approach with Einstein: Understanding and appreciating how our two organizations can support one other will help us realize the benefits of our relationship. We will agree upon an overarching co-branding approach to guide our joint program development efforts, including customized approaches for joint-operated initiatives.
7. Establish a co-fundraising approach with Einstein: To maximize philanthropic funding, we will prepare focused development plans for key program priorities and present our coordinated and aligned partnership to benefactors.

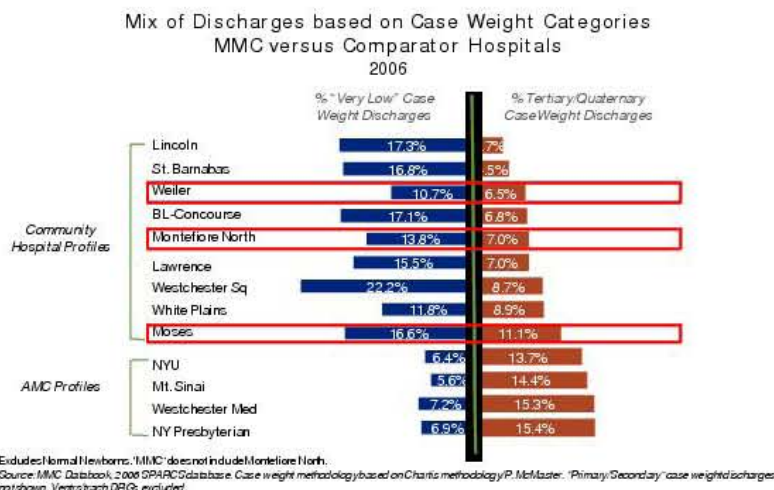
## 2. Create Notable Centers of Excellence

The second strategic goal focuses on the importance of creating and developing Centers of Excellence—hubs of multidisciplinary expertise and comprehensive services designed to deliver unparalleled, patient-centered care. Already, the close partnership between Montefiore and Einstein led to the creation of Centers of Excellence in Cancer Care, Cardiovascular Services, Transplantation and Neurosciences, as well as The Children's Hospital at Montefiore (CHAM). We plan to continue to build upon this success. For example, the CHAM model can be emulated within other disciplines and specialties to build our regional and national reputation across a number of clinical programs, enhance our standing as an academic medical center and attract more patients, many of whom live in the Bronx.

Most *U.S. News* Honor Roll Hospitals are academic medical centers, and all have six or more specialties ranked at the top or near the top of the specialty rankings. CHAM has enabled residents to receive outstanding care in the Bronx and has helped draw patients from

communities outside of the immediate vicinity. Developing other notable Centers of Excellence that follow the CHAM model and focusing on caring for patients with complex issues will enable us to better meet the needs of our community by attracting patients who currently leave the Bronx for medical services.

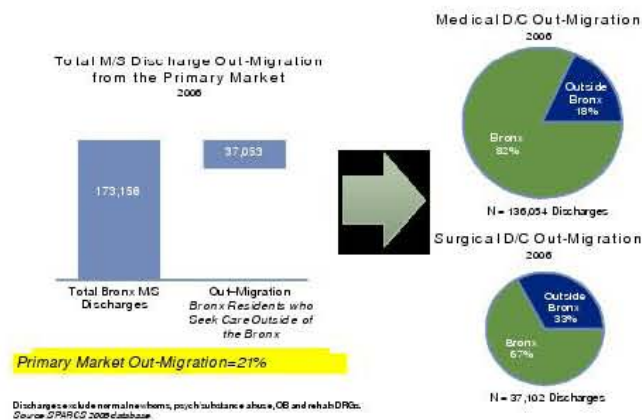
The expansion of Montefiore's notable Centers will help attract more high-case-weight patients and develop a higher case mix index, similar to other academic medical centers in our region, as shown below.



Twenty-three percent of Bronx residents currently leave the borough for inpatient care. Most of these patients go to Manhattan hospitals, driven by inadequate local access to high-end specialty care. Bronx hospitals are estimated to lose \$800 million annually in inpatient revenue because patients leave the borough to receive their care at other large academic medical centers, such as Columbia Presbyterian and Mount Sinai.

Complex surgical cases and other cases with high reimbursement rates leave the borough at a higher rate than less-complex medical cases. Montefiore's percentage of low-case-mix patients is much higher than that of comparable Manhattan-based academic medical centers. Providing added specialty services will bolster Montefiore's financial margins and further our mission. Montefiore's strategic goals support the development of high-quality tertiary care programs that will enable Bronx residents to receive a larger percentage of their healthcare closer to home.

A summary of the out-migration statistics for the Bronx for 2006 appears below. These outcomes are broken down by medical and surgical specialties.



To reduce out-migration, Montefiore has defined three broad strategic opportunities:

1. Continue to develop Centers of Excellence in Cancer Care, Cardiovascular Services and CHAM: Recent investments in each of these Centers have built a strong foundation that includes leadership, clinical excellence and a full portfolio of research capabilities, from basic science to clinical and translational research. With continued support, these service lines are well positioned to become recognized Centers of Excellence.
2. Develop additional Centers in Transplantation and Neurosciences: We will continue to expand our comprehensive and multidisciplinary services in transplantation and neuroscience, and build a market presence within these service lines. Targeted investments to build our clinical and research capabilities will ensure that they continue on the path to becoming notable Centers of Excellence.
3. Focus on building specialty services to support existing and other emerging Centers: High levels of service and access to specialty care are required to capture local and regional referrals that support the growth of our Centers. Different specialties will demand different tactics that range from new recruitments to productivity and efficiency initiatives.

### 3. Build Specialty Care Broadly

The current shortage of specialists in the Bronx provides Montefiore with an opportunity to grow and broaden its specialty care services. Montefiore is already in a strong position to move forward on this since it is the largest single employer of specialty care physicians in the Bronx. The New York State Department of Health has identified access to healthcare as a top priority. Access to ambulatory specialty care must be a top priority for Montefiore because the impact on the public's health can be significant.



A lack of access to these critical services can increase the chronic disease burden due to delayed identification and management of medical conditions and increase ambulatory-sensitive admissions—admissions that should be managed in the outpatient setting. Improved access could reduce the strain on Montefiore’s emergency departments, which patients use as a point of access for specialty care services.

The capabilities of the ambulatory system must also be enhanced to support specialty care growth. To keep pace with national ambulatory care trends, Montefiore will continue to support the development of joint ventures and other opportunities to improve access to ambulatory procedural centers. These projects, including the development of a community-based ambulatory surgery center, will help relieve hospital operating rooms and procedure areas while expanding the geographic reach of our delivery system.

Partnerships with other Bronx providers should be optimized to help us broaden specialty care access. We are working to enhance our relationships with other Bronx providers, allowing us to better manage specialty care resources and to create access to other acute care capacity. Over the long term, partnerships with other Bronx providers offer an opportunity to develop a borough-wide strategy to respond to the ambulatory and inpatient care needs of the community.

To achieve this goal, Montefiore will undertake the following three strategic initiatives:

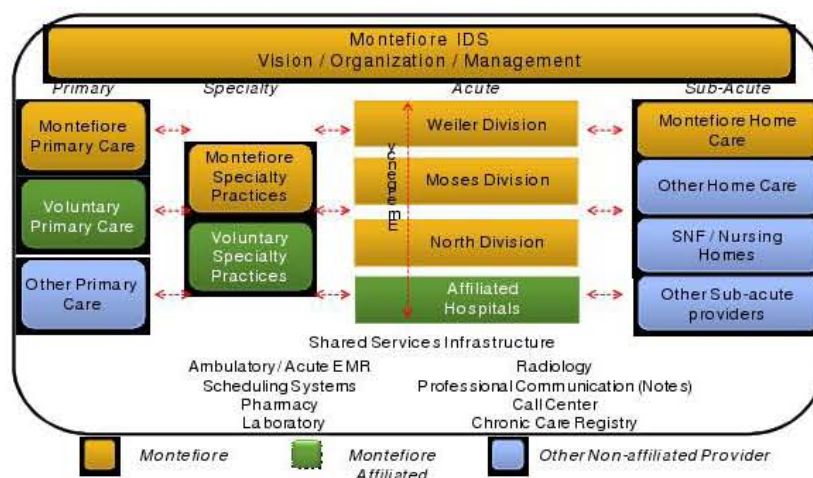
1. Increase access to a full spectrum of specialty services to meet the needs of the community: In addition to securing regional referrals for specialty services related to our Centers, we will enhance our specialty care capabilities in several areas to ensure that the Bronx community has sufficient local access to specialty care services.
2. Enhance infrastructure and staffing to support inpatient and outpatient specialty care growth: Over the coming years, specific types of acute care resources, such as intensive care unit beds, operating rooms, post-anesthesia care units and imaging technology, will be in higher demand. We will focus our efforts around improved utilization of our existing resources, as well as prudent investment in new resources. Gaps in our ambulatory services capabilities, including the creation of a community-based ambulatory surgery center, will be addressed. As infrastructure is developed, we will also recruit and retain highly skilled physicians, nurses, technicians and other healthcare providers. Continued training and support for our associates will enable them to more effectively manage the complex care needs of our patients.
3. Optimize hospital bed capacity: Opportunities exist to optimize bed capacity across our healthcare delivery system. For example, using the North Division capacity will offset demand at other locations, and continuing existing patient throughput initiatives will enhance efficiency and coordination of care. Our leadership team will evaluate opportunities for regionalization of key services and inpatient units in cases where clustering of services will lead to improved patient access and quality of care. Regionalization of key services is particularly important within our Centers of Excellence and in areas of care requiring specialized units, state-of-the-art technology and staff with specialized skills.

#### 4. Develop a Seamless Healthcare Delivery System with Superior Access, Quality, Safety and Patient Satisfaction:

Montefiore is well positioned to implement an integrated delivery system that advances health and enriches lives. We have made significant investments to expand and connect our system to provide patients with access to healthcare services across the continuum of care. We also have improved customer service and our performance along various quality metrics.

The breadth, depth and interconnectedness of our delivery system have the potential to distinguish us from local and national competitors. However, the system needs to be fine tuned to become even more integrated. For example, our delivery system operates frequently at or near capacity, and any system gaps can result in poor coordination among the delivery system components. Gaps in the system, such as a lack of consolidated scheduling, can also limit or delay access to specialty care.

A closely aligned, integrated delivery system will help Montefiore reduce out-migration and provide the highest quality care in the safest environment while managing costs.



Montefiore has extensive expertise in disease management and care coordination and can serve as a national model. Montefiore's ability to organize its delivery system around the needs of complex and chronically ill patients is essential.

To achieve this goal, Montefiore will undertake the following five strategic initiatives:

1. Migrate from managing episodes of care to a longitudinal health status management approach that emphasizes accountability: Effective coordination of our delivery system will enable us to streamline care across the system for our patients, rather than treating each patient encounter as an isolated episode. Building long-term

relationships with our patients will enable us to better manage their care and achieve superior outcomes, particularly for those with chronic disease. Achieving higher levels of system performance will lead to reduced out-migration and ensure that Montefiore remains a regional and national hospital of choice for patients and physicians.

2. Optimize the performance of all system components: To boost performance, we will enhance the primary care system, including access to prevention and screening, and work toward increasing the effectiveness of our physicians and hospitals in responding to and following up on specialty care referrals.
3. Continue to improve performance against peer groups in quality, safety and customer service: Over the past five years, Montefiore has made significant strides in creating systems to improve and better monitor quality, safety and customer service. We will continue to follow universal protocols and meet all compliance regulations, as well as meet and exceed the Center for Medicare and Medicaid Services' measures for quality. We will increase engagement and accountability for safety and quality among all clinical departments and all care providers and explore the use of metrics tied to incentives. Feedback will be key; we will continue to glean information from patient, physician and associate satisfaction surveys to drive performance.
4. Build and enhance infrastructure to strengthen the system: We will create a more consistent, seamless service experience for patients and referring physicians. Emphasis will be placed on "high-touch points" within the system, including scheduling, management of patient medical information, referral management and pre- and post-treatment physician communication. In addition to enhancing these areas, we will further develop shared services provided by the Care Management Organization to facilitate more effective management of patient relationships, particularly for patients with chronic diseases.
5. Improve care coordination and transition management: Existing care management capabilities will be enhanced to ensure that patients with multi-specialty care needs receive seamless care. The Centers of Excellence can serve as a model for highly coordinated, integrated care within the system. Transitions to and from the acute care setting will be managed more actively to improve access to care while reducing unnecessary hospitalizations. Potential areas for evaluation include centralized processes to manage out-of-system referrals and relationship development with skilled nursing facilities and other post-acute care providers.



### 5. Maximize the Impact of Our Community Service

Commitment to our social mission and to the community is our legacy and a great source of pride. We are nationally recognized for being a leader in developing innovative programs and research in community health, ranging from our school-based clinics to an NIH-funded center on health disparities.

Historically, Montefiore's community service programs have grown in a grassroots fashion and have evolved into sustainable, large-scale models that have had a significant impact on the Bronx. We seek to strengthen these programs by coordinating our efforts with community partners and evaluating program effectiveness. Federal and state governments require hospitals to organize, quantify and report on community service programs and outcomes. Specifically, at the federal level, new regulations require that we quantify and report on the level of our community benefit contributions. At the state level, regulations require that we focus on and demonstrate an impact in identified areas of high-priority health needs.

To help meet these requirements, Montefiore has identified five major strategic initiatives:

1. Establishing priorities based on identified community health needs: Montefiore will adopt a more strategic and systematic approach to evaluating, prioritizing and responding to community health needs to ensure that the full impact of our efforts is realized. In 2008, the New York State Department of Health identified 10 health priorities. Working from that list, we focused our 2009 Community Service Agenda on the following areas: obesity, diabetes, cancer, at-risk elderly, asthma and healthy babies, healthy mothers and healthy children. Montefiore will work with community partners and city and state officials to assess and meet the needs in these areas and to set future priorities. Targeted efforts will be made to build a comprehensive, coordinated presence in high-priority areas, while programs in other areas will continue to receive support.
2. Work with New York State to establish a sustainable model for the Bronx Regional Health Information Organization (RHIO): Significant strides have been made to establish a model RHIO in the Bronx. Support and development of the Bronx RHIO will help promote information exchange across Bronx-based providers. We will also continue to work closely with New York State to create a sustainable financial model for the RHIO and other health data exchanges across the state.
3. Strengthen stewardship and oversight: We will identify opportunities to strengthen oversight functions and accountability around community service. We will initiate a process to evaluate and report on the cost, benefits and sources of support for activities to better understand program effectiveness. We will also work with program organizers to clarify expectations around reporting and impact measurement, as well as to seek opportunities to better coordinate existing programs internally and with our community service partners.

4. Ensure that the delivery system further contributes to public health: We have an opportunity to improve health outcomes for our community and for generations to come through our continued efforts to provide longitudinal care to patients, particularly those with chronic disease. We will increase efforts to coordinate our community service activities with our clinical programs, such as cancer screening and patient education. Stronger connections between our healthcare delivery system and our community service activities will ensure that our patients and the community at large have access to comprehensive health-related services, from education and prevention to treatment and management.
5. Partner with Einstein on community-based research initiatives: Innovative community health programs provide a fertile setting for teaching and lay the foundation for groundbreaking social science, and behavioral and population-based research. Together, Montefiore and Einstein will explore opportunities to build and leverage a repository of best practice methodologies for community health programs and research publications.

#### Organizational Goals

##### **Organizational Goals**

- 1. Create a culture of high performance, motivation and fulfillment**
- 2. Maintain strong financial health**
- 3. Invest in state-of-the-art facilities and technologies**
- 4. Build an aligned and interconnected enterprise**
- 5. Foster supportive alliances and partnerships**

As with our Strategic Goals, Montefiore leadership has agreed upon five operational goals to advance our institution to new heights of excellence. These organizational goals focus on ways we can strengthen our institution from within, such as developing a high-performing workforce, investing in facilities and technology and strengthening internal relationships. Our organizational goals emphasize interconnectivity instead of individual components and accentuate the importance of our entire healthcare delivery system.



### 1. Create a Culture of High Performance, Motivation and Fulfillment

Successful implementation of the Strategic Plan relies on creating a high-performing, motivated and engaged workforce. This workforce must believe in our vision and mission and be motivated to deliver superior levels of quality service to our patients, their colleagues and to the community. Our medical staff, referring physicians and all associates understand and are committed to our culture of high performance. They will work together to create and deliver an experience that will both satisfy our traditional customer base and attract new patients.

To build and sustain this culture, we will galvanize our workforce around Montefiore's new Strategic Plan. We will recruit new associates with specialized skills and knowledge in order to support our needs and create new management systems—including structures, tools and incentives—to meaningfully engage and motivate our associates and create the ideal hospital experience. We will also turn to our voluntary medical staff and cultivate those relationships in order to satisfy patient preferences and build specialty care referrals. Developing a comprehensive approach to attracting and aligning our interests with those of non-affiliated physicians in our region will be critical to our success.

Quality and safety are central to ensuring that our workforce remains inspired and committed to our objectives. Investing in leadership development will equip our management team to succeed in their roles, take on additional responsibility, advance in the organization and inspire colleagues to do the same, which, in turn, will help support quality and safety measures.

### 2. Maintain Strong Financial Health

Montefiore will strengthen its financial health for three basic purposes: to generate capital for reinvestment in strategic initiatives, to support underfunded and mission-related programs and to hedge against future changes to our reimbursement levels and cost structures. We cannot rely on increased borrowing or philanthropy to fund strategic and mission-related investments.

To meet these three objectives, we will continue to improve our operating margin and manage our cost structures. To be self-supporting, the excess margin must grow from its current level of 1.3% to a more sustainable level of 3%, which is achievable and necessary if we successfully execute our Strategic Plan.

A 3% margin will enable Montefiore to support investments in additional Centers of Excellence, continue to upgrade its clinical equipment and IT systems, recruit leading clinicians and researchers, and renovate and build state-of-the-art facilities. A larger margin will also ensure the sustainability of our underfunded clinical and community service activities. Stronger margins can also support the development of specialty care programs, which will enable us to attract more high-acuity patients with favorable reimbursement levels. High-acuity patients will require more support, but we anticipate earning a higher margin per case based on the increased revenue.

Margins can be improved by effective management, such as stronger long-term oversight of our capitated patients' care across our healthcare delivery system. These initiatives can provide material improvement in our operating margins, allowing us to internally fund our strategic investments.

### 3. Invest in State-of-the-Art Facilities and Technologies

Improved margins would also support increased investment. Over the past five years, we have invested in infrastructure enhancements to meet the evolving standards of medicine and to maintain our competitive position in our local and regional markets. To be a premier academic medical center, we need to continue making infrastructure investments, which include building and maintaining the best facilities, equipment and information technology systems.

Our Strategic Plan calls for significant restructuring of our physical capacity, as well as investments in new facilities and technology. These investments will be carefully planned and timed to maximize impact on our operating results. A thoughtful and cogent master facilities plan will be created to identify how to best utilize current facilities and space, and to recommend infrastructure improvements for the future.

The constant evolution of healthcare equipment and technologies requires changes and upgrades to our existing inventory. For example, incremental investments in equipment and clinical technology will be necessary to build and develop the Centers of Excellence and specialty care programs. All of these needs will have to be considered, carefully evaluated and prioritized.

### 4. Build an Aligned and Interconnected Organization

We place great emphasis on our systems orientation—that all parts of Montefiore are important contributors, working together to provide care to individual patients as well as to the entire population. Over the coming decade, our focus will shift from the success of the individual parts of the system—primary care, specialty care and the four hospitals—to how the system functions as a whole.

To create an environment supportive of this more holistic approach to healthcare delivery, we will explore opportunities to improve alignment among physician, nursing and administrative leadership. We will work toward enhancing forums and vehicles for communication across the organization to support improved interconnectivity.

Information technology and systems, fundamental to all components of our current business model, are essential. We will continue to invest in information technology to ensure that accurate and current information is always available throughout the delivery system. Proposed areas of focus include continued roll-out and integration of the Electronic Medical Record system, evaluation of a uniform scheduling system, facilitation of research information sharing between Einstein and Montefiore, creation of systems to support acute care throughput, and the development of effective referral management systems, including coordinated and timely communication. These efforts will strengthen clinical decision-making and advance our long-term ability to manage patients and populations across all sectors of Montefiore's vast healthcare delivery system.

### 5. Foster Supportive Alliances and Partnerships

Internal and external partnerships are critical to becoming more effective and efficient. These partnerships include relationships among our own staff, as well as with Einstein, other healthcare providers, governmental agencies and community groups.

Montefiore's strong alignment with its 2,500 practicing physicians, the majority of whom are employed by the medical center, yields premium, cost-effective care, promotes community health and improves key outcomes. This approach is vital to physician recruitment and enhancing the access to quality healthcare throughout the region. We will continue by partnering with our own faculty and medical staff to cultivate specialty care services; to improve the quality, safety and continuity of care; and to better meet the community's needs. The creation of the Montefiore Integrated Provider Associations (IPA) is a recent example of a successful internal partnership. This hospital-physician partnership is key to our managed care strategy and to the development of our community-based centers in the east and west Bronx, and it has allowed us to expand access to specialty procedures, such as gastrointestinal procedures. Moving forward, Montefiore must be prepared to identify and pursue similar opportunities for hospital and medical staff collaborations and other joint ventures that add value to our healthcare delivery system.

Montefiore recognizes the increasing importance of working with other hospitals, health centers, nursing homes, physician groups and insurers/payers. We share common agendas with these groups, and we have worked together to identify areas of shared interest and achieve outcomes that could not have been accomplished alone. The Bronx RHIO is one example of such an effort, in which Montefiore partnered with other Bronx providers to create a regional clinical data exchange that has the potential to greatly improve the quality, safety and cost effectiveness of the care we provide. There are now, and will continue to be, many other opportunities for mutually beneficial collaborations.

## V. Looking Forward

Montefiore leadership understands that the determinants of health go well beyond the provision of medical care and that they are driven by a combination of social, economic and environmental factors. We have responded to health problems in the past, including child abuse, lead poisoning, HIV and tuberculosis—and we have partnered with other organizations within and outside of the formal healthcare system to design and implement effective interventions. Our Strategic Plan builds on this legacy and creates a blueprint for continued success.

## **Appendix B**

### **The APN's Role in the Cardiogenetics Clinic**



**MONTEFIORE MEDICAL CENTER**

The University Hospital for the  
Albert Einstein College of Medicine

N-3

**JOB DESCRIPTION**

<b>1. POSITION TITLE:</b> Nurse Practitioner	<b>Position Number:</b>
<b>EMPLOYEE'S NAME:</b>	
<b>SUPERVISOR'S NAME AND TITLE:</b>	
<b>DATE PREPARED:</b> 7/9/97	<b>DATE REVIEWED:</b> 9/11
<b>ORGANIZATION:</b>	
<b>DIVISION:</b> MMC	<b>DEPARTMENT:</b> <b>LOCATION:</b>
<b>APPROVALS:</b>	
<b>DEPARTMENT:</b>	<b>HUMAN RESOURCES      COMPENSATION:</b>
<b>2. SUMMARY OF POSITION:</b> The Montefiore NP maintains standards of the practice for nursing as defined by the American Nurses Association Code of Ethics, Nursing Scope and Standards of Practice and Nursing's Social Policy Statement.  The NP actualizes the vision, mission, values, balanced scorecard performance measures for Montefiore Medical Center.  The NP participates in performance improvement/research activities; maintains professional practice standards and clinical expertise; and demonstrates leadership skills. The NP demonstrates core and unit specific competencies based on the patient population served.  The Nurse Practitioner will assess and provide care to a selected group of patients in collaboration with physicians. The NP will be responsible for carrying out the plan of care for his/her patient panel. The NP contributes to the actualization of the philosophy and objectives of the specific Division/Department. He/she practices within the scope of practice in care delivery. He/she participates in performance improvement and research activities, and maintains professional practice standards and clinical expertise.	
<b>3. EDUCATION, TRAINING &amp; EXPERIENCE:</b> A. New York State License for a Registered Professional Nurse and current registration or valid permit to practice in New York State as an RN. B. Current New York State Nurse Practitioner specialty certification and registration. C. Master's or post Master's Certificate in specialty as a nurse practitioner preferred; or a combination of education and experience that is acceptable to N.Y. State Education Department and the Director of Nursing and/or Chairman of the Department, or Division Director. D. National certification in nurse practitioner specialty (ie: ANCC, AACNP or NAPNAP) preferred. E. Additional education as required by specialty/patient care location F. Effective English communication skills, both written and oral G. Ability to use data entry and retrieval system	

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<b>4. MOST FREQUENT CONTACTS</b>	<b>NATURE OR PURPOSE:</b>
A. Patients/Families/Involved Others	Assessment, care management, direct patient; patient/family/involved others education; evaluation of outcomes and long term planning.
B. Interdisciplinary Professionals (Includes Community resources)	Collaboration regarding plan of care
C. Team Members	Communicate in order to collaborate, coordinate, and maintain continuity and quality of care.
D. Other Service Associates	Coordinate and expedite plan of care; problem solving.
E. When applicable: Graduate Students/ Interdisciplinary Professionals	Education
<b>5. INDEPENDENT JUDGEMENT</b> <ul style="list-style-type: none"> <li>Assess the clinical status of patients in panel of care.</li> <li>Supervise an unexpected emergency in location of care.</li> <li>Analyze the results of tests ordered.</li> <li>Assess the clinical status of assigned patients and initiate any immediate care that is indicated.</li> <li>Identify actual or potential quality issues.</li> <li>Assess the appropriateness of plan of care and resource utilization.</li> <li>Assess and prescribe appropriate medications as per protocols.</li> </ul>	
<b>6. EQUIPMENT OPERATION:</b> <ul style="list-style-type: none"> <li>Use of patient care equipment</li> <li>Use of appropriate diagnostic equipment</li> <li>Use of automated clinical information system</li> </ul>	
<b>7. SPECIFIC DUTIES</b>	
<b>COMPETENCY</b>	<b>PERFORMANCE CRITERIA</b>
1. Performs and records a complete physical examination. ADA (X)  Balanced Performance Measure: Internal Process (IP)	A. Records are maintained in an accurate manner per chart review.
2. Obtains and records a complete health history. ADA (X)  Balanced Performance Measure: Internal Process (IP)	A. Appropriate care is provided as per standard of care.
3. In collaboration with physicians and other health care providers, coordinates care of patients and evaluates plan of care and patient toward health goals and modifies plan of care accordingly.	A. Appropriate care is provided as per standard of care and per collaborative practice agreement B. Plan of care is communicated to all members of the health care team.

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COMPETENCY	PERFORMANCE CRITERIA
<p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>C. Care is delegated to team members consistent with capabilities and responsibilities of caregiver.</p> <p>D. Monitors variances with plan of care.</p> <p>E. Assesses and reassesses patient and initiates appropriate interventions to amend identified variances from plan of care.</p> <p>F. Reviews plan of care and/or update it to reflect current status of the patient.</p>
<p>4. Collaborates with patient and/or involved others and/or agencies to formulate a plan of care.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP) Customer View (CV)</p>	<p>A. Appropriate plan is agreed upon between NP and involved others.</p> <p>B. A therapeutic relationship is established with patient and/or involved others.</p> <p>C. Identifies patient and/or involved others' satisfaction/dissatisfaction with plan of care.</p> <p>D. If the patient and/or involved others express dissatisfaction, NP implements conflict resolution skills, and escalates issues with plan of care.</p>
<p>5. Communicates effectively with involved others and members of the health care team.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Defends and preserves the rights of patients relative to all aspects of care, information, knowledge and privacy.</p> <p>B. Demonstrates respect for cultural diversity with patients, involved others, coworkers and other health care team members.</p> <p>C. Establishes collaborative and collegial relationships with health care members.</p> <p>D. Communicates plan of care to its assigned patients and involved others.</p> <p>E. Demonstrates behavior consistent with MMC code of respect.</p> <p>F. If appropriate and if on patient's primary care team, assess and documents advanced care directives for 100% of assigned patients. Obtains health care proxy and living will when able.</p> <p>G. Establishes collaborative and collegial relationships with health care team members.</p> <p>H. Identifies patient satisfaction/dissatisfaction with plan of care. If patient expresses dissatisfaction, implements conflict resolution skills, and escalates issues with plan of care.</p> <p>I. Documents legibly.</p>

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COMPETENCY	PERFORMANCE CRITERIA
<p>6. Orders, performs and interprets diagnostic procedures and tests with the scope of privileging.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Appropriate orders are completed and interpretations are made.</p>
<p>7. Develops and analyzes differential diagnoses based on clinical and laboratory data.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Appropriate analyses are made.</p>
<p>8. Participates in a team approach to health care by acting as liaison between subspecialist and other members of the primary care team. Communicates effectively with members of the health care team.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Maintains communication with the interdisciplinary team through frequent interactions and staff conferences.</p>
<p>9. Prescribes medications and educates the patient and/or involved others about the drug regimen, interactions and side effects.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Zero error tolerance.</p>
<p>10. Demonstrates critical thinking skills to problem-solve and initiate clinical decision-making.</p> <p>ADA (X)</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Assess patient's clinical status and attempts satisfactory resolution of patient's clinical needs.</p>
<p>11. Demonstrates responsibility for maintaining competencies.</p> <p>ADA (X)</p>	<p>A. Demonstrates responsibility for own practice and ongoing development, including participation in at least one continuing education program annually.</p>



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COMPETENCY	PERFORMANCE CRITERIA
Balanced Performance Measure: Innovation and Learning (IL)	<ul style="list-style-type: none"> <li>B. Supports goals and activities of the team within the patient care area and at the MMC.</li> <li>C. Contributes to the growth and development of staff and students through participation in peer review, mentor relationships, formal and informal education.</li> <li>D. Participates in educational experiences within the practice setting.</li> <li>F. Participates in activities contributing to the growth and development of self, colleagues and the nursing profession.</li> <li>G. Attends inservice(s) as appropriate for maintaining current practice standards.</li> </ul>
12. Is responsible and accountable for own practice. ADA (X)  Balanced Performance Measure: Innovation and Learning (IL)	<ul style="list-style-type: none"> <li>A. Critical thinking/problem solving is incorporated into nursing practice.</li> <li>B. Contributes to problem identification and problem solving in the work environment, participating in task forces and groups as necessary.</li> <li>C. Supports the mission, vision, critical success factors and goals of Montefiore Medical Center and the standards for nursing practice.</li> <li>D. Conforms to the MMC dress code.</li> <li>E. Conforms with MMC attendance and punctuality policy.</li> </ul>
13. Performs related duties as necessary. ADA (X)  Balanced Performance Measure: Internal Process (IP)	<ul style="list-style-type: none"> <li>A. Appropriate care is provided per plan of care.</li> </ul>
14. Provides a safe environment for patients/involved others. ADA (X)  Balanced Performance Measure: Internal Process (IP)	<ul style="list-style-type: none"> <li>A. Orients patient/involved others to environment, assuring comprehension of information presented.</li> <li>B. Administers medication error free.</li> <li>C. Responds appropriately in an urgent/emergent situation.</li> <li>D. Utilizes equipment in accordance with MMC policies and procedures.</li> </ul>
15. Demonstrates leadership skills in the coordination and delivery of patient care. ADA (X) Balanced Performance Measure: Internal Process (IP)	<ul style="list-style-type: none"> <li>A. Coordinates an interdisciplinary of care.</li> <li>B. Assures 100% of patient panel have a documented plan of care.</li> <li>C. Delegates care of the patient to team members consistent with the capabilities and responsibilities of caregiver.</li> </ul>

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<b>8. SPECIALIZED SKILLS AND TECHNICAL COMPETENCIES</b>	
<b>TECHNICAL COMPETENCY &amp; SPECIALIZED SKILL</b>	<b>PERFORMANCE CRITERIA</b>
16. Knowledge of aseptic care in all procedures performed.  Balanced Performance Measure: Internal Process (IP)	A. Maintains aseptic technique for all procedures performed.
17. Knowledge of and ability to perform special procedures as relative to practice.  Balanced Performance Measure: Internal Process (IP)	A. Appropriately performs special procedures. B. Competency is assessed by either certifying body and/or supervising colleague.
18. Collection of specimens for microscopic, bacteriologic and viral studies (urine, sputum, vaginal, cervical, etc.)  Balanced Performance Measure: Internal Process (IP)	A. Collects specimens appropriately.
19. Test interpretation.  Balanced Performance Measure: Internal Process (IP)	A. Accurately interprets test results.
20. Administers medication in clinical site when appropriate.  Balanced Performance Measure: Internal Process (IP)	A. Zero error tolerance.
<b>9. AGE SPECIFIC SKILLS AND COMPETENCIES</b>	
<b>COMPETENCY</b>	<b>PERFORMANCE CRITERIA</b>
21. Demonstrates knowledge and skills necessary to provide care appropriate to the age of the patients served.  Balanced Performance Measure: Internal Process (IP)	A. Assess and interprets data relative to the age status of the patient; differentiates between normal age parameters and abnormal parameters.
22. Knowledge and ability to prescribe pharmacologic agents related to the age of the patient served.  Balanced Performance Measure: Internal Process (IP)	A. Dosage conforms to appropriate age, weight and renal functional guidelines.

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<b>9. AGE SPECIFIC SKILLS AND COMPETENCIES</b>	
<b>COMPETENCY</b>	<b>PERFORMANCE CRITERIA</b>
<p>23. Establishes a teaching and long-term plan based on documented patient/involved others learning needs, chronological maturation, emotional status and cognitive ability.</p> <p>Balanced Performance Measure: Internal Process (IP)</p>	<p>A. Utilizes specific information in the development of teaching and long term plans.</p> <p>B. Documents patient/involved others' response to teaching/long term planning.</p> <p>C. Evaluates and documents patient/involved others' response to teaching/long term plan.</p>
<b>Standards of Behavior</b>	
<p>24. Integrates the standards of excellence into daily clinical practice.</p> <p>Balanced Performance Measure: Internal Process (IP) Customer View (CV) Innovation and Learning (IL) Financial Goals (FG)</p>	<p>Consistently demonstrates:</p> <p>A. <b>Respect:</b> Honors and values each person.</p> <p>B. <b>Effective Communication:</b> Effectively listens, conveys, and receives ideas, information, and direction.</p> <p>C. <b>Sensitivity:</b> Demonstrates willingness and ability to listen and understand others' feelings, needs and circumstances.</p> <p>D. <b>Professionalism:</b> Demonstrates confidence, competence and pride in work and appearance.</p> <p>E. <b>Exceeding Expectations:</b> Assists others without being asked.</p> <p>F. <b>Courtesy:</b> Treats everyone with kindness and care.</p> <p>G. <b>Teamwork:</b> Builds cooperative, constructive working relationships.</p>
<p>25. Non-Clinical/Technical Competencies</p>	<p>Consistently demonstrates:</p> <p>A. <b>Customer Focus/Service Orientation:</b> Meets patient/customer needs in timely, positive, and professional manner.</p> <p>B. <b>Quality of Work:</b> Work performed is consistently accurate and thorough and at the expected level.</p> <p>C. <b>Problem Solving:</b> Identifies and carefully assesses situation/information/data before taking action within scope of practice and/or licensure/certification.</p> <p>D. <b>Time Management:</b> Uses his or her time effectively and efficiently. Work is accomplished at the expected volume/level.</p> <p>E. <b>Initiative:</b> Takes timely and appropriate action in accordance with defined job responsibilities and operating within scope of practice and/or licensure/certification.</p>

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<b>Standards of Behavior</b>		
	F. <b>Dependability:</b> Associate requires minimum supervision, carries through effectively on all work assignments; is reliable; usually present and on time.	
<b>10. WORK LEADER RESPONSIBILITY:</b>	<b>YES</b>	<b>NO</b>
1. DOES THIS POSITION HAVE WORK LEADER RESPONSIBILITY?	<b>X</b>	
2. DOES THIS POSITION INVOLVE ANY OF THE FOLLOWING: SELECT, TERMINATE, TRAIN EVALUATE OR DISCIPLINE SUBORDINATE EMPLOYEES OR EFFECTIVELY RECOMMEND THESE ACTIONS?		<b>X</b>
3. DOES THIS POSITION PLAN, ASSIGN, SCHEDULE AND REVIEW WORK ASSIGNMENTS OF OTHER EMPLOYEES?	<b>X</b>	
4. LIST THE NUMBER OF SUBORDINATE EMPLOYEES THAT THIS POSITION LEADS AND DIRECTS AND LIST THEIR TITLES AND NAMES, BELOW, <u>IF ANY</u> . Number of Employees = Various	<b>X</b>	
5. PLEASE DESCRIBE THE NATURE OF THE LEADERSHIP RESPONSIBILITIES OF THIS POSITION, <u>IF ANY</u> This position has leadership responsibility when appropriate and according to location; participates in leading, collaborating, and delegating to registered nurses, licensed practical nurses, technical support staff and team members in the planning, evaluating and implementation of patient care. Monitors patient care delivery systems and processes.		
<b>11. ENVIRONMENTAL WORKING CONDITIONS:</b>		
<ul style="list-style-type: none"> <li>• Patient care locations.</li> <li>• Potential exposure to hazardous materials including potential exposure to blood and body fluids.</li> <li>• Potential exposure to communicable diseases.</li> </ul>		
<b>12. PHYSICAL REQUIREMENTS</b>		
<ul style="list-style-type: none"> <li>• May be required to move patients.</li> <li>• May be required to set up exam room (location specific)</li> </ul>		
<b><u>PHYSICAL REQUIREMENTS</u></b>		
A. Position requires bending, lifting, reaching, standing. Walking, sitting, manual dexterity, and respond quickly to a variety of situations and for an extended period of time.		
B. Visual, oral and cognitive ability to assess patient and environmental status.		

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***Clinical Professional and Licensed Technical Associate  
Nurse Practitioner Performance Evaluation***

<b>Associate's Name:</b>	<b>Associate #:</b>	<b>Evaluation Period:</b>
		<b>From: To:</b>
<b>Associate's Position:</b>	<b>Department:</b>	
<b>Appraiser Name:</b>	<b>Appraiser's Position:</b>	

### **I. Job Responsibilities/Individual Development Goals Assessment**

#### **Instructions:**

List the key job responsibilities for this associate. Note: It is important that the responsibilities listed be consistent for all associates performing the same job.

Indicate the balanced scorecard domain that is related to each key job responsibility- Innovation and Learning (IL), Internal Process (IP), Customer View (CV), Finance and Growth (FG).

Describe how the associate performed the key job responsibilities and whether he or she demonstrates the requisite and expected level of knowledge based on his or her education, training, and experience.

Assess the extent to which the individual met each key job duty's requirements specifying whether he or she:

- Underperformed/Failed to meet requirements (1).
- Partially met requirements/Needs to improve (2)
- Achieved or met requirements (3)
- Exceeded requirements (4)
- Significantly exceeded requirements (5)

Provide an overall assessment or summary rating at the end of the section using the same scale as above.

In the Individual Development Goals section comment on any development goals that were set at the beginning and/or during the evaluation period and whether and the degree to which they have been achieved.

<b>Job Responsibility</b>	<b>Balanced Scorecard Domain</b>	<b>Performance Description</b>	<b>Performance Assessment</b>
1. Performs and records a complete physical examination.	IP	A. Records are maintained in an accurate manner per chart review.	
2. Obtains and records a complete health history.	IP	A. Appropriate care is provided as per standard of care.	
3. In collaboration with physicians and other health care providers, coordinates care of patients and evaluates plan of care and patient	IP	A. Appropriate care is provided as per standard of care and per collaborative practice agreement.	
	IP	B. Plan of care is communicated to all members of the health care team.	

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Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
toward health goals and modifies plan of care accordingly.	IP	C. Care is delegated to team members consistent with capabilities and responsibilities of caregiver.	
	IP	D. Monitors variances with plan of care.	
	IP	E. Assesses and reassesses patient and initiates appropriate interventions to amend identified variances from plan of care.	
	IP	F. Reviews plan of care and/or update it to reflect current status of the patient.	
4. Collaborates with patient and/or involved others and/or agencies to formulate a plan of care.	IP, CV	A. Appropriate plan is agreed upon between NP and involved others.	
	IP, CV	B. A therapeutic relationship is established with patient and/or involved others.	
	IP, CV	C. Identifies patient and/or involved others' satisfaction/dissatisfaction with plan of care.	
	IP, CV	D. If the patient and/or involved others express dissatisfaction, NP implements conflict resolution skills, and escalates issues with plan of care.	
5. Communicates effectively with involved others and members of the health care team.	IP	A. Defends and preserves the rights of patients relative to all aspects of care, information, knowledge and privacy.	
	IP	B. Demonstrates respect for cultural diversity with patients, involved others, coworkers and other health care team members.	
	IP	C. Established collaborative and collegial relationships with health care members.	
	IP	D. Communicates plan of care to its assigned patients and involved others.	
	IP	E. Demonstrates behavior consistent with MMC code of respect.	

Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
<p>6. Orders, performs and interprets diagnostic procedures and tests with the scope of privileging.</p> <p>7. Develops and analyzes differential diagnoses based on clinical and laboratory data.</p> <p>8. Participates in a team approach to health care by acting as liaison between sub specialist and other members of the primary care team. Communicates effectively with members of the health care team.</p> <p>9. Prescribes medications and educates the patient and/or involved others about the drug regimen, interactions and side effects.</p> <p>10. Demonstrates critical thinking skills to problem-solve and initiate clinical decision-making.</p>	IP	F. If appropriate and if on patient's primary care team, assess and documents advanced care directives for 100% of assigned patients. Obtains health care proxy and living will when able.	
	IP	G. Establishes collaborative and collegial relationships with healthcare team members.	
	IP	H. Identifies patient satisfaction/dissatisfaction with plan of care. If patient expresses dissatisfaction, implements conflict resolution skills, and escalates issues with plan of care.	
	IP	I. Documents legible.	
	IP	A. Appropriate orders are completed and interpretations are made.	
	IP	A. Appropriate analyses are made.	
	IP	A. Maintains communication with the interdisciplinary team through frequent interactions and staff conferences.	
	IP	A. Zero error tolerance.	
	IP	A. Assess patient's clinical status and attempts satisfactory resolution of patient's clinical needs.	
	IP		



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Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
11. Demonstrates responsibility for maintaining competencies.	IL	A. Demonstrates responsibility for own practice and ongoing development, including participation in at least one continuing education program annually.	
	IL	B. Supports goals and activities of the team within the patient care area and at the MMC.	
	IL	C. Contributes to the growth and development of staff and students through participation in peer review, mentor relationships, formal and informal education.	
	IL	D. Participates in educational experiences within the practice setting.	
	IL	E. Participates in activities contributing to the growth and development of self, colleagues and the nursing profession.	
	IL	F. Attends inservice(s) as appropriate for maintaining current practice standards.	
12. Is responsible and accountable for own practice.	IL	A. Critical thinking/problem solving is incorporated into nursing practice.	
	IL	B. Contributes to problem identification and problem solving in the work environment, participating in task forces and groups as necessary.	
	IL	C. Supports the mission, vision, critical success factors and goals of Montefiore Medical Center and the standards for nursing practice.	
	IL	D. conforms to the MMC dress code.	
	IL	E. Conforms with MMC attendance and punctuality policy.	
13. Performs related duties as necessary.	IP	A. Appropriate care is provided per plan of care.	
14. Provides a safe environment for patients/ involved others.	IP	A. Orients patient/involved others to environment, assuring comprehension of information presented.	



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Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
	IP	B. Administers medication error free.	
	IP	C. Responds appropriately in an urgent/emergent situation.	
	IP	D. Utilizes equipment in accordance with MMC policies and procedures.	
15. Demonstrates leadership skills in the coordination and delivery of patient care.	IP	A. Coordinates an interdisciplinary of care.	
	IP	B. Assures 100% of patient panel have a documented plan of care.	
	IP	C. Delegates care of the patient to team members consistent with the capabilities and responsibilities of caregiver.	
16. Knowledge of aseptic care in all procedures performed.	IP	A. Maintains aseptic technique for all procedures performed.	
17. Knowledge of and ability to perform special procedures as relative to practice.	IP	A. Appropriately performs special procedures.	
	IP	B. Competency is assessed by either certifying body and/or supervising colleague.	
18. Collection of specimens for microscopic, bacteriologic and viral studies (urine, sputum, vaginal, cervical, etc.)	IP	A. Collects specimens appropriately.	
19. Test interpretation.	IP	A. Accurately interprets test results.	
20. Administers medication in clinical site when appropriate.	IP	A. Zero error tolerance.	
21. Demonstrates knowledge and skills necessary to provide care appropriate to the age of the patients served.	IP	A. Assess and interprets data relative to the age status of the patient; differentiates between normal age parameters and abnormal parameters.	
22. Knowledge and ability to prescribe pharmacologic agents related to the age of the patient served.	IP	A. Dosage conforms to appropriate age, weight and renal functional guidelines.	
23. Establishes a teaching and long-term plan based on documented patient/involved others learning needs, chronological maturation, emotional status and cognitive ability.	IP	A. Utilizes specific information in the development of teaching and long term plans.	

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Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
	IP	B. Documents patient/involved others' response to teaching/long term planning.	
	IP	C. Evaluates and documents patient/involved others' response to teaching/long term plan.	
		<i>Overall Assessment</i>	
<b>Individual Development Goals</b>			

## II. Non-Clinical/Technical Competency Assessment

**Instructions:** For each of the **behaviors and competencies** evaluate the individual's performance in the context of the goals and objectives accomplished and how they were accomplished as well as in how the individual carried out his or regular job responsibilities.

Assess the extent to which the individual met each key job duty's requirements specifying whether he or she:

- Underperformed/Failed to meet requirements (1).
- Partially met requirements/Needs to improve (2)
- Achieved or met requirements (3)
- Exceeded requirements (4)
- Significantly exceeded requirements (5)

### Behavior/Competency Continuum

Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
24. Integrates the standards of excellence into daily clinical practice.	IL, CV, IP, FG	Consistently demonstrates: A. Respect: Honors and values each person	
	IL, CV, IP, FG	B. Effective Communication: Effectively listens, conveys, and receives ideas, information, and direction.	
	IL, CV, IP, FG	C. Sensitivity: Demonstrates willingness and ability to listen and understand others' feelings, needs and circumstances.	

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Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
	IL, CV, IP, FG	D. Professionalism: Demonstrates confidence, competence and pride in work and appearance.	
	IL, CV, IP, FG	E. Exceeding Expectations: Assists others without being asked.	
	IL, CV, IP, FG	F. Courtesy: Treats everyone with kindness and care.	
	IL, CV, IP, FG	G. Teamwork: Builds cooperative, constructive working relationships.	
25. Non-Clinical/Technical Competencies	IL, CV, IP, FG	Consistently demonstrates: A. Customer Focus/Service Orientation: Meets patient/customer needs in timely, positive, and professional manner.	
	IL, CV, IP, FG	B. Quality of Work: Work performed is consistently accurate and thorough and at the expected level.	
	IL, CV, IP, FG	C. Problem Solving: Identifies and carefully assesses situation/information/data before taking action within scope of practice and/or licensure/certification.	
	IL, CV, IP, FG	D. Time Management: Uses his or her time effectively and efficiently. Work is accomplished at the expected volume/level.	
	IL, CV, IP, FG	E. Initiative: Takes timely and appropriate action in accordance with defined job responsibilities and operating within scope of practice and/or licensure/certification.	
	IL, CV, IP, FG	F. Dependability: Associate requires minimum supervision, carries through effectively on all work	

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Job Responsibility	Balanced Scorecard Domain	Performance Description	Performance Assessment
		assignments; is reliable; usually present and on time.	
	IL, CV, IP, FG	G. Specify number of absences and lateness' for this appraisal period. Absence (sick: _____ Lateness: _____	

## III. Clinical Professional/ Licensed Technical Competency Assessment

Instructions:

- List each of the competencies that are being assessed or validated. Competencies listed should be consistent for all associates in the same job. **(As an alternative to completing this section, you may substitute and attach any pre-filled or customized competency assessment form that is in use for jobs within your area.)**
- Make any comments or observations in conjunction with the assessment of the competency.
- Specify the validation method: **D** - discussed and reviewed; **DEMO** – demonstrated; **ED**: Completed educational program, in-service training; **T**- tested orally or in writing; **E**- evidenced in daily work; **PR** – peer review; **P**- presentation; **R** – records review (progress notes, medical records); **Q** –qualification (online verification of current licensure, registration, certification, etc.); **DOC**- documentation (associate provides documentation verifying educational qualifications, certification, registration); **O** = other
- Indicate the date that the competency was validated and who validated the competency
- Specify age and/or population groups:
  - Age Groups: **1** – neonatal/Infancy (birth – 1 year); **2** – pediatric (1-11 years); **3**- Adolescent (12-17 years); **4** – Adult (18-65 years); **5**-geriatric (65+ years)
  - Population Groups: **C**= cultural; **E**=Ethnic; **R**=Religious/faith based; **D**= disease specific

Competency	Comments (Indicate whether the associate <u>Meets or Does Not</u> <u>Meet Competency</u> )	Validation Method	Date Validated and Assessor	Indicate Age/ Population Group
<b>CORE COMPETENCY</b>				
Staff Nurse: Nursing process competency validation				
CIS Documentation				
Fall Reduction				
Montefiore Service Excellence				
Medication Administration				
Pain Assessment and Management				
Pressure Ulcer Assessment and Management				
Ventilator Management				

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Competency	Comments (Indicate whether the associate <u>Meets</u> or <u>Does Not</u> <u>Meet</u> Competency)	Validation Method	Date Validated and Assessor	Indicate Age/ Population Group
Emergency Preparedness				
Safety				
Cardiopulmonary Resuscitation				
<b>Unit Based Competency</b>	Comments (Indicate whether the associate <u>Meets</u> or <u>Does Not Meet</u> Competency requirement)	Validation Method	Date Validated and Assessor	Indicate Age/ Population Group
<b>POSITION BASED COMPETENCY</b>				

If applicable, has this associate completed Annual Mandatory Training? Check Yes \_\_\_ or No \_\_\_. If No, please specify as a goal with a timeframe for completion in the Individual Development Plan section of this evaluation. Please attach transcript reflecting what has been completed to date.

#### IV. Individual Development Plan

**Instructions:** Improved individual work performance is the key driver of improved organizational effectiveness. Individual development planning provides a structure for mutually identifying an individual's development goals and the action steps needed to achieve them. Development plans should focus on maintaining areas of performance strength and areas requiring performance improvement.

1. Review the overall ratings and comments within each section of this assessment form and determine the major performance patterns and themes including whether the individual is an Exceeding, Achieving, or Underperforming associate. Identify this individual's high priority opportunities for development. Consider options for preparing this individual for new responsibilities or remedial actions where he or she may not currently be meeting expectations.
2. Identify the area, related development goal, and specific action steps that will result in improved performance and/or growth, and mutually develop action steps that are specific, measurable, and date-referenced.
3. Schedule follow-up meetings to review individual's progress.



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Area of Opportunity (Note Job Duty, Competency, Standard of Behavior or Skill Area)	Improvement/Development Goal (Describe specific desired performance and criteria to determine whether improvement or development has occurred)	Action Steps to Achieve Goal* (Include due date for achievement)

\*Consider developmental options *within* Montefiore (e.g. coaching and project assignments) as well as external resources.

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<b>V. OVERALL PERFORMANCE ASSESSMENT</b>				
<b>Instructions:</b> Taking into account how the individual carried out his or her regular job responsibilities, the results accomplished for each goal/objective and the assessment of the associate's competencies and adherence to the core standards of behavior assign an overall rating of performance for the evaluation period by placing an "X" in the column which best describes the associate's overall performance.				
<input type="checkbox"/> <b>Underperforming</b>  Failed to meet requirements. Consistently performed below expectations. (1)	<input type="checkbox"/> <b>Needs improvement.</b>  Performed some job duties proficiently and demonstrated proficiency in some Non-Clinical Competencies and Standards of Behavior. Needs remedial instruction on some Clinical competencies. (2)	<input type="checkbox"/> <b>Achieving.</b>  Meets requirements. Performed most job duties proficiently and demonstrated proficiency in most Non-Clinical Competencies and Standards of Behavior. All Clinical competencies validated. (3)	<input type="checkbox"/> <b>Exceeds.</b>  Performed all job duties proficiently and demonstrated proficiency in all Non-Clinical Competencies and Standards of Behavior. All Clinical competencies validated. (4)	<input type="checkbox"/> <b>Significantly exceeds.</b>  Demonstrated excellence in performing all job duties as well as in Non-Clinical Competencies and Standards of Behavior. All Clinical competencies validated. (5)

<b>Summary Comments on Overall Work Performance</b>
<b>Instructions:</b> Narrative should include specific factors influencing results (i.e. unplanned work, special or additional assignments, factors outside associate's control, etc.)
<b>Appraiser's Comments:</b> <div style="border: 1px solid black; height: 100px; width: 100%;"></div>

Appraiser's Signature \_\_\_\_\_ Date \_\_\_\_\_

Reviewer's Signature & Title \_\_\_\_\_ Date \_\_\_\_\_

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**Associate's Comments:**

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I understand that my signature attests only to the fact that I have seen this performance appraisal and it has been explained to me. It does not necessarily indicate that I agree with this appraisal.

\_\_\_\_\_  
Associate's Signature

\_\_\_\_\_  
Date

Note: Please file the original completed/signed evaluation in the associate's departmental file; notify Human Resources of the evaluation



## **Appendix C**

### **Standards of Practice for Nurse Practitioners**



## Standards of Practice for Nurse Practitioners

### **Administration**

P.O. Box 12846 • Austin, TX 78711  
p 512.442.4262 • f 512.442.6469  
[www.aanp.org](http://www.aanp.org)

### **Office of Health Policy**

P.O. Box 40130 • Washington, DC 20018  
p 202.966.6414 • f 202.966.2856



## Standards Of Practice

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### I. Qualifications

Nurse Practitioners are licensed independent practitioners who provide primary and/or specialty nursing and medical care in ambulatory, acute and long term care settings. They are registered nurses with specialized advanced education and clinical competency to provide health and medical care for diverse populations in a variety of primary care, acute and long term care settings. Master's, post master's or doctoral preparation is required for entry level practice. (AANP 2006)

### II. Process of Care

The nurse practitioner utilizes the scientific process and national standards of care as a framework for managing patient care. This process includes:

#### A. Assessment of health status

The nurse practitioner assesses health status by:

- obtaining a relevant health and medical history
- performing a physical examination based on age and history
- performing or ordering preventive and diagnostic procedures based on the patient's age and history
- identifying health and medical risk factors

#### B. Diagnosis


The nurse practitioner makes a diagnosis by:

- utilizing critical thinking in the diagnostic process
- synthesizing and analyzing the collected data
- formulating a differential diagnosis based on the history, physical examination, and diagnostic test results
- establishing priorities to meet the health and medical needs of the individual, family, or community

#### C. Development of a treatment plan

The nurse practitioner, together with the patient and family, establishes an evidence based, mutually acceptable, cost-awareness plan of care that maximizes health potential.

Formulation of the treatment plan includes:

- ordering and interpreting additional diagnostic tests
  - prescribing/ordering appropriate pharmacologic and non-pharmacologic interventions
  - developing a patient education plan
  - appropriate consultation/referral
- 

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**D. Implementation of the plan**

Interventions are based upon established priorities.

Actions by the nurse practitioners are:

- individualized
- consistent with the appropriate plan for care
- based on scientific principles, theoretical knowledge, and clinical expertise
- consistent with teaching and learning opportunities

Actions include:

- accurately conducting, supervising, and interpreting diagnostic tests
- prescribing/ordering pharmacologic agents and non pharmacologic therapies
- providing relevant patient education
- making appropriate referrals to other health professionals and community agencies

**E. Follow-up and evaluation of the patient status**

The nurse practitioner maintains a process for systematic follow-up by:

- determining the effectiveness of the treatment plan with documentation of patient care outcomes
- reassessing and modifying the plan with the patient and family as necessary to achieve health and medical goals

**III. Care Priorities**

The nurse practitioner's practice model emphasizes:

**A. Patient and family education**

The nurse practitioner provides health education and utilizes community resource opportunities for the individual and/or family

**B. Facilitation of patient participation in self care.**

The nurse practitioner facilitates patient participation in health and medical care by providing information needed to make decisions and choices about:

- promotion, maintenance, and restoration of health
- consultation with other appropriate health care personnel
- appropriate utilization of health care resources

**C. Promotion of optimal health**

**D. Provision of continually competent care**

**E. Facilitation of entry into the health care system**

**F. The promotion of a safe environment**

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**IV. Interdisciplinary/Collaborative Responsibilities**

As a licensed independent practitioner, the nurse practitioner participates as a team leader and member in the provision of health and medical care, interacting with professional colleagues to provide comprehensive care.

**V. Accurate Documentation of Patient Status and Care**

The nurse practitioner maintains accurate, legible, and confidential records.

**VI. Responsibility as Patient Advocate**

Ethical and legal standards provide the basis of patient advocacy. As an advocate, the nurse practitioner participates in health policy activities at the local, state, national and international levels.

**VII. Quality Assurance and Continued Competence**

Nurse practitioners recognize the importance of continued learning through:

- participation in quality assurance review, including systematic review of records and treatment plans on a periodic basis
- maintenance of current knowledge by attending continuing education programs
- maintenance of certification in compliance with current state law
- applying standardized care guidelines in clinical practice

**VIII. Adjunct Roles of Nurse Practitioner**

Nurse practitioners combine the roles of provider, mentor, educator, researcher, manager and consultant. The nurse practitioner interprets the role of the nurse practitioner to individuals, families, and other professionals.

**IX. Research as Basis for Practice**

Nurse practitioners support research by developing clinical research questions, conducting or participating in studies, and disseminating and incorporating findings into practice.

## **Appendix D:**

### **Informed Consent**

**St. John Fisher College**

#### **INFORMED CONSENT FORM**

**Title of study: The Lived Experiences of Families that Have Attended a Cardiogenetics Center. Under NIH original grant #2009-460-004: Ethical & Social Implications of Genetic Testing in the Case of Unexpected Deaths. Amendment approved and dated 4/14/2011-7/20/2011**

Name(s) of researcher(s): Esma D. Paljevic, CPNP

Faculty Supervisor: Mary Alice Donius, Ed.D., RN

Program Director: Ronald Valenti, PhD

Phone for further information: Esma Paljevic 718-741-2327

Purpose of study:

The purpose of this study is to better understand your personal experiences of experiencing sudden cardiac death in someone in your family. Additionally, this study seeks to understand how this specialized clinic has affected you and your family. You, as research participants, will be

asked to discuss your experiences about sudden cardiac death and your time spent with the Cardigenetics Clinic and what it means to you.

Study Procedures:

Examples of the questions that you be asked in the interview are:

1. Tell me the story of your family member's experience with SCD?
2. Tell me the story of your experience with the Montefiore Cardiogenetics

Approval of study: This study has been reviewed and approved by the St. John Fisher College Institutional Review Board (IRB).

Place of study: The Children's Hospital at Montefiore Medical Center. Cardiogenetics Center. 3415 Bainbridge Ave Bronx, NY 10467. For your participation in this study you will be asked to meet with the researcher once for an in depth interview/discussion about you r experiences. The approximate length of thisone time interview session, may last from 1-2 hours

Risks and benefits: The expected risks and benefits of participation in this study are explained below:

- There may or may not be direct medical benefit to you from being in this research study.
- Possible benefits are that you may feel support and empathy while participating in the interview.
- In addition, the information learned from this study may, in the future, benefit other people with the same medical condition.
- You may become upset from talking about difficult experiences such as the death of a family member, or the fact that your family may be at risk for having a genetic condition associated with sudden death.

Method for protecting confidentiality/privacy:

- The research records will be kept private and your name will not be used in any written or verbal reports.
- The research records will be kept in a secured manner and computer records will be password protected.
- Support for this study is being supplied by: National Institutes of Health.
- Your research records and medical records may be inspected by members of the research team, and the study sponsor (The National Institutes of Health). The people who reviewed this research study as members of the Albert Einstein College of Medicine Committee on Clinical Investigations (CCI) and the Montefiore Medical Center Institutional Review Board (IRB) may also review your research and medical records. All of these people have agreed to keep your information private and not to use this information for anything other than the purposes of this study.
- All of these groups have been agreed to keep your name private.
- Results of the study may be presented at professional meetings, or published in journals. None of your identifying information will be included in these presentations or publications in order to protect your privacy.

**Your rights:** As a research participant, you have the right to:

1. Have the purpose of the study, and the expected risks and benefits fully explained to you before you choose to participate.
2. Withdraw from participation at any time without penalty.
3. Refuse to answer a particular question without penalty.
4. Be informed of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to you.
5. Be informed of the results of the study.

I have read the above, received a copy of this form, and I agree to participate in the above-named study.

Print name (Participant)

Signature

Date:



Print name (Investigator) Signature Date:

If you have any further questions regarding this study, please contact the researcher listed above. If you experience emotional or physical discomfort due to participation in this study, Dr. Louise Silverstein, a family psychologist, will be contacted and made available for support.