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Support of the Informal Kinship Care Family

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This is to certify that **Emily Hansen** has successfully defended her Graduate Project entitled **"Supporting Informal Kinship Care Families"** and fulfilled the requirements for the Master of Arts in Nursing degree.

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Abstract

Most children cannot imagine living without their parents; for some though, because of social instability, substance abuse, or parental neglect, life apart from their parents is the reality. When these children are cared for by a relative or a close family friend without the involvement of a child welfare agency, the family that is created is known as an informal kinship care family. Because of the fluid nature of these families, little is known about them, leaving this group disadvantaged and neglected by the health care community. After a review of the existing literature, observation of informal kinship care families, and conversations with informal kinship caregivers and children, a conceptual model is proposed to help identify the unique challenges of this neglected group and ensure the holistic and sustained well-being of the children and adults who make up the informal kinship care family. The proposed model uses Margaret Newman's Theory of Health as Expanding Consciousness and the strengths of transcultural nursing to widen the definition of the patient and redefine health to include a holistic view. The key concepts of holism, relationship, hope, and transformation are explored and used to deepen the meaning of the model. After implementation and evaluation, the goal is that families cared for under the model will experience transformation and sustained well-being.

Keywords: family, holism, informal kinship care, transformation, transcultural nursing

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When I began this project so many months ago, I imagined it would be just one more paper in a string of papers that mark my time in the Master of Arts in Nursing program. It turns out that this has been so much more than just a paper; it has been a journey, and one that I would not have completed without the support of many people.

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Chapter One: Introduction

Most children cannot imagine living without their parents; for some though, because of social instability, substance abuse, or parental neglect, life apart from their parents is the reality. In many cases relatives or a close family friend are called upon to be a surrogate parent, often termed a kinship caregiver. Occasionally the children are removed from their parents' care by a child welfare agency. However, in the majority of cases, the movement of a child from the parents' care to a relative's care is decided between parties without an outside agency's involvement, an arrangement called informal kinship care. Though the majority of children living in kinship care are in informal kinship care arrangements, most of the literature excludes this subset of families (Goodman et al., 2004; Simpson & Lawrence-Webb, 2009). Because the transfer of children by agreement between parties happens outside of any formal child welfare system, the specific challenges and needs of the children and their kinship caregivers may not be fully understood leaving this population alone and vulnerable in facing great challenges (Simpson & Lawrence-Webb, 2009). As a result, a model is proposed to identify the unique challenges of this neglected group and develop a system of support to ensure the holistic and sustained well-being of the children and the adults who unexpectedly become their kinship caregivers.

Background

In 2011, this author became one of these unexpected parents to two teenaged girls. Though unrelated, both girls underwent life crises in the spring of that year that placed them in uncertain and unstable living situations. For the remainder of this paper,

these girls will be referred to as Damiya and Anaria, pseudonyms they chose in order to protect their identities. For Damiya, the precipitating life event involved her father, her primary caretaker, being incarcerated for an extended period of time leaving her with limited options of where to live for the remainder of her teenage years. Meanwhile, Anaria's home life was becoming increasingly chaotic, aggravated by her frequent attempts at running away and refusal to follow the rules at home, leading her parents to seek an alternate living situation for her. Already in a relationship with the girls and their families, I both sought and was called upon to offer support during the upheaval they were experiencing. Though not my initial intent, by the fall of that year I was the primary caretaker of both girls.

With this major life change, both the girls and I experienced emotional and physical challenges. Due to personal histories of trauma and loss, both girls had existing emotional and behavioral problems that were exacerbated as they dealt with the loss of their families while adapting to a new home and school along with new expectations and schedules that accompanied them. For me, despite my education and training as a nurse, meeting the physical and emotional needs of the girls led to high levels of stress, financial strain, and general feelings of being overwhelmed by the changes. With the unfamiliar struggles and life changes, every aspect of my life was impacted. The balance of physical, mental, and emotional well-being was upset for both the girls and me, with their struggles affecting me and my struggles affecting them.

As this imbalance occurred, one of the specific challenges encountered was meeting the girls' physical and mental health needs. Though I had a notarized Power of Attorney document verifying my right to make decisions, including health care, for the

girls, it remained difficult to access care as health care facilities, schools, and community resources questioned our custody arrangement. Nearly every time it was necessary to go to a clinic, a hospital, or attempt to get special education support through the school, multiple hurdles needed to be overcome in order to access the care on behalf of the child. When we did manage to gain the attention of professionals, they typically addressed only one small portion of a much larger underlying issue, leading to fractured care that failed to address the core of the girls' or my needs.

This was particularly true for Anaria who had been diagnosed with mental and behavioral health disorders at a young age. Prior to moving in with me, the process of getting a social worker involved to better meet Anaria's mental, behavioral, and emotional needs had begun. With the change in caretaker, the organization that provided the social work services refused to continue its greatly needed involvement unless the girl's mother was willing to participate as well. Because her mother refused, Anaria's case was closed. Though Anaria has significant behavioral and emotional needs, securing services in the clinic and community proved difficult. Even with my experience and skills as a nurse and active community member, attempting to identify and access resources unassisted was challenging. Without effective services and support, Anaria's behavioral problems escalated and her mental health status deteriorated to the point that continuing in my home was no longer an option.

Unfortunately the situation described above is not unique. It is estimated that 2.3 million children in the United States live with relatives or close family friends, an arrangement described as kinship care (The Urban Institute, 2002). Kinship care is further divided into three categories: kinship foster care, voluntary kinship care, and

informal kinship care (Messing, 2006). Kinship foster care and voluntary kinship care are initiated when a child welfare agency removes children from their parents' custody. In kinship foster care, the relative is licensed under the supervision of a child welfare agency, whereas in voluntary kinship care there is no licensure. However, in the case of informal kinship care, the child is living outside of the parents' home through an agreement between the parents and the caregiver without any involvement of an outside child welfare agency (Messing, 2006). The majority of children living in kinship care fall under the last category with over 1.7 million children in the United States estimated to be living in informal kinship care arrangements (The Urban Institute, 2002).

Though the research on children and families involved in informal kinship care is limited, the literature available indicates that the challenges and needs of those in informal kinship care are similar to those in formal foster care (McLean & Thomas, 1996). Children live apart from their parents because of a crisis or an unstable social situation such as substance abuse, incarceration, mental illness, abuse, neglect, or death of a parent (Letiecq, Bailey, & Porterfield, 2008). The behavioral, mental health, and medical needs of the children experiencing these life traumas mirror those of the children in foster care (McLean & Thomas, 1996). Many informal kinship caregivers experience challenges related to feeling unprepared and not having adequate time to transition to full time caregiving (Letiecq et al., 2008).

The uncertainty of permanency can cause strain for both the child and the caregiver. Many children and caregivers hope that one or both of the biologic parents will eventually be able to resume care of the child. Even when this is unlikely, caregivers are often reluctant to seek more permanent custody arrangements because of the potential

for conflict with the biologic parents (Messing, 2006). Because of the nature of informal kinship care and the complex family issues that are usually present, kinship caregivers are unable to plan for the future or seek necessary services for the child due to the uncertainty of when the parents will return to care for their child (Letiecq et al., 2008). This ambiguity combined with the complex needs of the child can lead caregivers to learn about available services in a haphazard manner, often missing out on available resources and assistance (Letiecq et al., 2008).

Despite being the most common form of kinship care and facing the same challenges as those under the supervision of child welfare agencies, families involved in informal kinship care are often the least supported (McLean & Thomas, 1996). Families within the formal foster care system are provided with financial assistance, social service programs, physical and mental health services, school related services, child care, legal counseling, and respite services (Letiecq et al., 2008). Informal kinship caregivers, on the other hand, are left to identify and access health and social services unassisted even though the child in their care has the same physical, behavioral, and mental health needs (McLean & Thomas, 1996). While many families view it as a benefit to be outside the supervision of a child welfare agency, this also leaves them disadvantaged because they are not eligible for services that the child in their care desperately needs (Messing, 2006). For those caregivers seeking help, there is very little information available about social and health care services for families involved in informal kinship care, contributing to the difficulty that families have in identifying appropriate care. This difficulty is especially true when trying to navigate complex eligibility and financial requirements independently (Simpson & Lawrence-Webb, 2009). Trying to meet the high needs of the child while

adapting to a new family structure and pattern has the potential to create greater levels of stress and dysfunction and a general breakdown in the wellbeing of the child, caregiver, and family as a whole.

Transcultural Nursing

It will be demonstrated in the following chapter that, though the needs of this population are great, much of this need stems from the basic lack of support and care that takes into account the unique context of the informal kinship care family. Though multidisciplinary care certainly has its place in supporting these families, transcultural nurses hold a key position in providing care. Madeleine Leininger (2006), the mother of transcultural nursing, describes the unique position of the nurse. She says:

> Nursing is a dynamic field of study and practice that takes into account culture, religion, social change, and multiple factors that influence health and wellbeing. It is a profession with discipline knowledge to help people, whether ill or well, with their diverse care needs. (p. 17)

In providing care, the transcultural nurse understands that the wider context of the individual, family, and community needs to be understood and addressed to truly achieve wellness. Transcultural nursing provides care that is not simply seeking to alleviate physical symptoms but to bring people to a place of sustained physical, mental, and spiritual wellness.

Transcultural nursing focuses on providing broad, holistic, culture-specific care to all people, giving deliberate attention to neglected cultures (Leininger & McFarland, 2006). While falling under the category of informal kinship care family may by default make these families a neglected culture, many of these families are already in a place of

disadvantage before they become informal kinship care families. The social problems that lead to biologic parents being unable to care for their child are largely associated with low-income communities (Grant, 2000). While intergenerational caregiving is increasing for all racial and ethnic groups in the United States, informal kinship caregivers are most likely to be African Americans living in poverty (Bunch, Eastman, & Griffin, 2007). Ignoring the social and cultural dynamics of these families will lead to fractured care that does not succeed in bringing about sustained wellness for the individual or family as a whole. This broad understanding of health and its connection to the environment and wider context places transcultural nurses in a leadership position for creating improved systems of care for complex and neglected populations such as informal kinship care families.

Theoretical Framework

In order to assist informal kinship caregivers and the children in their care to adapt to new challenges and patterns of operating, Margaret Newman's (1994) Theory of Health as Expanding Consciousness will be used as the theoretical framework to support the model proposed in chapter three. In this theory, health is not the absence of conflict or disease nor is it a continuum with wellness on one extreme and illness on the other, as in most Western models of health. According to Newman (1994), health is a pattern of the whole individual and the individual's interactions with the environment. When people are faced with a crisis or a change in life or their environment, their existing pattern of operating becomes disrupted. Illness appears when the old ways of interacting with the environment no longer work, forcing the individual to form new patterns as he or she finds a new understanding of how things must now work in order to function. Health

is achieved as the individual expands his or her understanding and is able to participate in the creation of new patterns of being. To state it another way, every person, no matter how disordered, is a part of a process of finding greater meaning in life and of finding new ways of being connected to other people and the greater environment. Wellness and illness are manifestations of this process of changing and evolving patterns.

The role of the nurse functioning under the Theory of Health as Expanding Consciousness centers on pattern recognition (Newman, 1994). In order to do this, a paradigm shift is required. This shift begins with changing the primary goal of nursing from addressing disease and its symptoms to helping people identify their expanding patterns. The view of disease changes from a negative force, to recognizing it as a process of reorganization in which a person develops new ways of functioning (Newman, 1994).

The focus on evolving patterns makes this theory especially applicable in the support of kinship caregivers and the children in their care. In response to the crises and changes that kinship caregivers and the children experience, all parties involved are suddenly faced with a situation in which the old ways of functioning no longer work. The challenges for both caregiver and child found in the literature reflect the difficulty they experience as they attempt to face new challenges and uncertain realities. This theory can guide the nurse in supporting the caregiver and child in developing patterns that achieve wellness for the caregiver and child individually, in relationship with one another, and with the wider community.

Children living apart from their parents and the loved ones called upon to become their caregivers face enormous challenges. Despite the prevalence of children being

raised by family members or friends outside of the supervision of a child welfare agency, informal kinship caregiving families are left to face these challenges alone. The unmet physical, behavioral, and mental health needs of this group create a demand for a system of support within the community and health care system to lift the strengths of these families up and support them through the changes and pursuit of wellness. The following chapter will provide further evidence from the literature regarding the unique challenges that informal kinship care families face to their physical, mental, and spiritual well-being. The evidence from the literature, the personal experiences of the author, and information shared by informal kinship care families all support the need for an improved system utilizing holistic care to promote sustained wellbeing for this neglected population.

Chapter Two: Review of Relevant Literature

In order to effectively support informal kinship caregivers and the children they are charged with, it is necessary to understand the unique strengths they carry and complex challenges they encounter. Though there are gaps in the literature regarding this population, it is known that both the caregivers and the children face a multitude of mental and behavioral health issues. In order to address the health concerns comprehensively and holistically, it is necessary to understand the underlying legal system and health care system that often act as barriers to wellbeing for informal kinship caregiving families.

Though the ratio of children in informal kinship care to formal kinship care is six to one, little is known about this subset of kinship care (Gibson & Singh, 2010; Strozier & Krisman, 2007). The very nature of informal kinship care, family members making arrangements without child welfare oversight, makes it difficult to obtain accurate estimates regarding this population (Strozier & Krisman, 2007). Studies that attempt to widen the knowledge base regarding informal kinship care find it difficult to obtain a sample that is representative of the population (Strozier & Krisman, 2007). Of the available literature, the majority of the studies examine grandparent caregivers, in particular maternal grandmothers, but fail to explore other informal kinship caregivers such as aunts, uncles, older siblings, or close family friends (Gleeson et al., 2009).

Though there are gaps in the literature concerning informal kinship caregivers and the children they care for, it is possible to glean important information from the existing literature about the characteristics and challenges of this neglected population. In comparison to formal foster caregivers, informal kinship caregivers are more likely to be

female, unmarried, less educated, unemployed, and African American (Sheran & Swann, 2007; Strozier & Krisman, 2007). It is predicted that children come into informal kinship care from the same precipitating factors as children who go into formal foster care (Grant, 2000). These reasons include parental substance abuse, neglect, abuse, abandonment, homelessness, incarceration, mental or physical illness, death, teen pregnancy, and divorce (Glass & Huneycutt, 2002; Gleeson et al., 2009). Though a parental crisis is the catalyst for a child coming under the care of a relative or friend, informal kinship caregivers also have internal motivations that influence their decision to accept the caregiving role (Gleeson et al., 2009). These motivations are diverse and complex but include reasons such as a distrust of the child welfare system, spiritual influences, obligation, a desire to give the child a sense of belonging or an attempt to keep the child safe (Gleeson et al., 2009). Gleeson et al. (2009) found that in some instances family members attempted to involve child protective services initially, but when these agencies failed to act, the family member took in the child. Though informal kinship caregivers have many motivations for assuming the care of a child, the goodwill of the caregivers can be stretched to the breaking point by the high needs of the child and the behavior of the biologic parents (Saunders & Selwyn, 2008).

Child Mental, Physical, and Behavioral Health Issues

It is well documented that children who experience traumatic life events have a higher risk of developing mental, emotional, and behavioral health problems (Anderson, 2011; Edwards, 2006). One study found that children raised by their grandparents are more frequently referred for psychiatric treatment due to depression, oppositional-defiant behavior, attention deficit hyperactivity disorder, temper tantrums, mood swings, social

isolation, concentration problems, aggression, and suicide attempts (Edwards, 2006; Mclean, Kettler, Delfabbro & Riggs, 2012; Tarren-Sweeney, 2008). A study specifically looking at children in kinship care because of parental incarceration, found that the children exhibited symptoms of post traumatic stress disorder, depression, anger, and guilt (Hanlon, Carswell, & Rose, 2007). These children report long-term problems from the trauma of separation from their birthparents and as a result have problems forming emotional attachments with their new caregivers (Hanlon et al., 2007).

These poor mental health outcomes can be explained in part by the trauma from frequent moves and separation from family (Anderson, 2011). A strong association has been found between placement instability and mental health problems, with more frequent moves associated with a deterioration of mental health (Anderson, 2011; Tarren-Sweeney, 2008). Children of incarcerated parents are found to have an average of three caregivers during their lifetime. Even with these caregivers being known to the child, each change in caregiver requires an adjustment in order to adapt to the new home, new style of parenting, and new school (Anderson, 2011). Informal kinship care tends to coincide with frequent conflict between birthparents and the kinship caregiver, which results in greater feelings of instability and conflict for both child and caregiver (Grant, 2000).

Poor mental health outcomes tend to be associated with poor school performance and poor functioning in society. Childhood exposure to trauma is thought to affect development of attachment, self-control, moral judgment, and social judgment, which can lead to maladaptive beliefs and behaviors (Hanlon et al., 2007). These children have higher levels of delinquent behaviors such as substance abuse, sexually risky behaviors,

school suspensions, and arrests (Tarren-Sweeney, 2008; Taussig & Clyman, 2011). A study examining teachers' perceptions of problems in children being raised by their grandparents found that teachers perceived significantly higher levels of behavior problems in children raised by their grandparents and were more often referred to guidance counselors and school administrators because of the excessive amounts of teachers' energy they consumed (Edwards, 2006). Children in out-of-home care have a higher rate of learning difficulties and poorer education outcomes (Tarren-Sweeney, 2008). The frequent complaints from teachers and referrals to special education services that follow behavior problems at school often lead caregivers into a system that can be overwhelming and challenging (Grant, 2000). Whether from placement instability or other trauma, if left without effective intervention, children in informal kinship care families tend to have poor educational and mental health outcomes (Mclean et al., 2012).

Caregiver Health Issues

Just as trauma and instability often result in mental health problems for children, these traumas and unexpected life changes have mental and emotional health consequences for informal kinship caregivers as well. In fact, grandparent informal kinship caregivers have twice the rate of clinical depression and anxiety as traditional grandparents (Langosch, 2012). Another study, though not using clinical definitions of depression, found that caregivers reported diminished interests in activities, fatigue, and loss of energy; all symptoms consistent with depression (Neely-Barnes, Graff & Washington, 2010). In addition to depression, grandparent kinship caregivers are more likely to report greater limitations of daily activities, lower levels of marital satisfaction, poorer health, and lower levels of self esteem (Bunch et al., 2007; Strozier & Krisman,

2007). Among informal kinship caregiving grandmothers, exhaustion and stress are the most commonly reported health problems (Fitzgerald, 2001). A relationship has been found between greater health needs of the child and poorer mental and physical health of the caregiver (Neely-Barnes et al., 2010).

These increased caregiver mental health issues likely stem directly from stresses related to caregiving as well as from the change in lifestyle and daily routines that occur when incorporating full time caregiving into their lives (Bunch et al., 2007). Often caregivers have little time to prepare for the drastic change to their life plans and find themselves unprepared to cope with the emotional and mental health problems of the children they care for (Fitzgerald, 2001; Gleeson et al., 2009). The changes that occur in the caregiver's life often lead to feelings of social isolation and of being unsupported by family members and friends (Bunch et al., 2007). Some informal kinship caregivers indicate that other family members desire to help, but because of their own problems such as health issues or financial difficulties, they are not able to follow through on being a support (Simpson & Lawrence-Webb, 2009).

Other sources of stress arise from the complex family situations that inevitably coexist with informal kinship care arrangements (Kelch-Oliver, 2008). Boundaries and roles are often not negotiated between the birthparents and the caregiver, leading to conflict as the birthparents are intermittently involved in a way that the caregiver may find disruptive (Brown et al., 2000). Caregivers often experience anger, ambivalence, or resentment towards the child's birthparents for being unable or unwilling to care for the child (Kelch-Oliver, 2008).

A common theme throughout the literature is loss. Children lose their parents and caregivers lose their freedom, social life, social status, financial security, and a healthy relationship with the child's birthparents (Fitzgerald, 2001; Szinovacz, DeViney & Atkinson, 1999). One study found that one-fourth of the respondents reported giving up more of their lives than they had expected to in order to care for the child (Sheran & Swann, 2007).

The stress, exhaustion, anxiety, and depression common among informal kinship caregivers often lead to other health problems (Fitzgerald, 2001; Szinovacz et al., 1999). Clinicians have documented increased insomnia, hypertension, and back and stomach problems related to the physical and emotional demands this population experiences (Minkler & Roe, 1996). Caregivers, specifically grandparents, rarely seek treatment when the transition to caregiving is the precipitating problem (Kelch-Oliver, 2008). While the strains of caregiving likely lead to an increased need for health care, many caregivers, particularly grandparent caregivers, neglect their own health needs because of the burden of caring for the child (Grant, 2000). For example, in the face of increased financial demands, some informal kinship caregivers stop purchasing their diabetes or heart medications, hearing aids, or glasses in order to first meet the needs of the child (Strozier & Krisman, 2007).

Many informal kinship care families experience this financial hardship, particularly when the child has physical or mental health problems (Saunders & Selwyn, 2008; Szinovacz et al., 1999). Due to the demands of full time caregiving, some caregivers find it necessary to take unexpected time off, reduce their work hours, or quit their jobs altogether (Szinovacz et al., 1999). While the majority of informal kinship care

families are eligible for financial assistance, studies reveal that only one in five utilize the assistance because they are not aware of the available resources (Sheran & Swann, 2007). This lack of information and awareness of available resources is common among informal kinship caregiving families and will be discussed in more depth later in this chapter.

Legal Issues

A major source of stress and instability for informal kinship caregiving families is the complex custody situation (Grant, 2000). Caregivers put themselves in a precarious position when they assume the role of caregiver without having any legal rights (Gibson & Singh, 2010). Though having these rights is necessary in order to access health care, initiate social services, and enroll the child in school, most informal kinship caregivers operate without formalized legal rights (Gibson & Singh, 2010). Typically the birthparents retain their legal rights, giving them the right to come and go from their child's life as it suits them, lending to a sense of instability for both caregiver and child (Gibson & Singh, 2010). There is a high risk for the children in informal kinship care arrangements to repeat a cycle of abrupt and frequent change in caregiving between the birthparents and the informal kinship caregiver at the whim of the birthparents (Gibson & Singh, 2010). As long as the birthparents retain their legal rights, they not only have the ability to claim and return their child as they please, they also have the right to claim financial assistance even if that money is not being used for the care of the child (Glass & Huneycutt, 2002). The general lack of policy regarding informal kinship care families often leaves them in a precarious legal and economic situation with few options within the federal, state, and local government to turn to for help (Gibson & Singh, 2010).

Regardless of the length of time that a parent is absent, there is no pathway for custody to be automatically transferred to the informal kinship caregiver (Gibson & Singh, 2010). In order to gain custody, informal kinship caregivers must go to court to have the birthparents' rights terminated which is time consuming and expensive (Gibson & Singh, 2010). For many families the ultimate goal is for the child to be able to return to their parents' care at a later time, which may prevent the informal kinship caregiver from seeking legal custody while the child is in his or her care (McLean & Thomas, 1996). In addition to the time and money that court proceedings consume, many informal kinship caregivers fear that initiating legal proceedings will cause further conflict with the child's birthparents, perhaps prompting the parent to take the child away from the caregiver into an unstable or unsafe living situation (Gibson & Singh, 2010). In most states, courts presume that the parents should have custody and tend to favor reunification with the parents even when it does not appear to be in the best interest of the child (Glass & Huneycutt, 2002; Grant, 2000).

Health Care Insurance and Access

Just as navigating the legal system can be challenging, so can operating within the complex health care system. Although informal kinship caregivers face the same daunting mental health challenges as those within the child welfare system, they must work unassisted to access and navigate necessary services (Mclean & Thomas, 1996). Nonrelative formal foster parents have access to a wealth of support and resources including medical and psychiatric evaluation and treatment (Glass & Huneycutt, 2002). There is a general attitude by agencies however that kinship caregivers stepped into the

role voluntarily and therefore should be able to manage unassisted (Saunders & Selwyn, 2008).

Informal kinship caregivers not only lack services, they lack information regarding what services are available and whether or not they are eligible for them (Carr, Hayslip & Gray, 2012; Strozier & Krisman, 2007). Community services for this population have been found to be both limited and restrictive in eligibility (Hanlon et al., 2007). For mental health services in particular, there tends to be a circular logic in which mental health service providers demand placement stability for the child before they will begin services (Mclean et al., 2012). The children in informal kinship care sometimes never truly gain placement stability to the degree that mental health providers require. It has been found that caregivers under greater stress are less likely to access support services, leading to the assumption that when the burden of caregiving increases, caregivers may not have the energy or insight that is needed to educate themselves about what services are available (Carr et al., 2012). In one study, families reported that they needed education, referrals to services, and emotional support, but the greatest need was for information (Strozier & Krisman, 2007). In comparison to formal foster care families, informal kinship caregiving families receive less training, less support, and fewer services (Strozier & Krisman, 2007). Those families that do succeed in accessing the healthcare system report challenges dealing with service providers and complex financial and insurance requirements (Carr et al., 2012).

Though obviously a necessary component to accessing health care, maintaining health insurance can be complicated for these families. While children within the child welfare system receive full health insurance, there is no placement-based entitlement for

children in informal kinship care placements (Raghaven et al., 2009). Raghaven et al. (2009), found that children are at risk of being dropped from insurance when transitioning between caregivers. Discontinuation of insurance, no matter how temporary, leads to higher rates of delayed care, unmet medical needs, and unfilled prescriptions (Raghaven et al., 2009). It is common that therapy is interrupted during the transition from birthparents to informal kinship caregiver, specifically because of confusion over or loss of medical insurance (Grant, 2000). Families forced to pay out of pocket for mental and physical health services experience increased economic stress, which can compromise access to health care and adequate nutrition (Grant, 2000).

In order to ensure the health and wellness of informal kinship caregivers and children, it is important to understand the strengths and challenges underlying these circumstances. Any approach to support this population must be multifaceted in order to adequately bolster the strengths and address the core of the challenges of this population. In the following chapter a model is proposed that takes into account the context of informal kinship care families and promotes a system of care that holistically meets the physical and emotional needs of the child and caregiver.

Chapter 3: Development of the Practice Model

The overwhelming challenges that informal kinship care families experience resound with this author's personal experience of being an informal kinship caregiver. Though formally educated, situated in a strong support system, grounded in a firm faith base, and considered successful by most people, I found myself feeling more and more isolated, overwhelmed, and anxious in the face of what felt like an ongoing uphill battle with the emotional needs, behavioral problems, and social conflict of the girls in my care. As a nurse, I understood the health care system and yet found myself in cycles of referrals to different systems of care such as mental health professionals, social workers, and special education specialists, none of which truly met the girls' or my needs in an efficient or effective manner. Although medical care, mental health care, therapy, and social work support was provided to the standard expected in the professional community, each failed to take into account the context of the family and the underlying issues, leading to inadequate care that did not meet the core of our needs.

Throughout the data gathering process of this paper, several informal kinship care families were either observed or informally interviewed and shared similar frustrations over the ongoing emotional, behavioral, or social health issues they faced and the difficulty in securing understanding and comprehensive care. Though these families and the literature presented in the previous chapter mirror my experience and confirms that I am not isolated in my need for improved care, the health care community has largely neglected the needs of informal kinship care families. These families, often already at a disadvantage due to racism, poverty, and living in low-income communities, face further disadvantages as they seek help in a system that does not understand the complexities of

the informal kinship care family. All of these factors provide evidence of the need for a new way to meet and support informal kinship care families in their pursuit of wellness. With this in mind, the concepts of transcultural nursing and Newman's Theory of Health as Expanding Consciousness are used to create a new approach to providing holistic care to informal kinship care families that encourages sustained wellbeing for the child, the informal kinship caregiver, and the family as a whole.

Introduction of the Practice Model

In order to effectively support informal kinship care families, nurses must think about and approach these families in new ways. This new model involves understanding the context of the family, redefining and broadening the definition of the patient, utilizing a holistic definition of health, and creating a trusting relationship with the child and caregiver. The broadened definitions, deeper understanding of the informal kinship care family, and reliance on relationship, holism, hope, and transformation provide the foundation for The Model of Support for the Informal Kinship Care Family that will be presented here.

Care within the Western health system typically operates in a compartmentalized fashion; physical wellness is treated separately from mental wellness, just as the caregiver's needs are separated from the child's needs. For informal kinship care families, though the Western health care system may attempt to compartmentalize the areas of health and wellness, the reality is that physical and mental health, as well as child and caregiver, are inseparable. This interconnectedness can be demonstrated in many ways. Caregivers who are struggling with the demands of caregiving while simultaneously dealing with depression, anxiety, or social isolation, may be unable to

cope with the physical or mental health needs of the child in their care leading them to seek services and health care for the child. Though for the purposes of the health care facility the presenting need is an issue with the child, the actual impetus for seeking care is the decreased ability of the caregiver to cope. Simply treating the child with medical care without providing the caregiver with support or improved strategies to address the caregiver's personal emotional needs or the child's needs, will not bring wellness to the child, caregiver, or family. Another scenario is a child acting out in response to conflict or instability in the home. A school may refer the child for more behavioral or mental health services, however these services will likely be ineffective unless care and services are provided to both child and caregiver in order to help the family identify and resolve the source of the conflict. A final example is of a caregiver who presents to a health care facility due to high blood pressure that worsens after a particularly challenging period of time of dealing with a child who is failing to cope with the emotional loss of a parent who recently resurfaced only to leave again. If the child does not receive care alongside the caregiver for this emotional instability, it is likely the high blood pressure will only be medicated without truly treating the cause. For the members of an informal kinship care family, the physical and emotional health problems are often a result or reflection of conflict or imbalance in the home or the wider social fabric of the child's biologic parents.

Redefining the Patient

The previous scenarios indicate the incomplete and fractured care given under the current definition of patient. The proposed new approach to the informal kinship care family is based on the idea that the patient is not only the individual presenting with the

physical or mental disease, but includes the child, caregiver, and family as a whole. While each family member is an individual, each is in a relationship that cannot be ignored or only partially treated. Though the initial complaint of the child or caregiver must be addressed, the transcultural nurse must also recognize that the one presenting with the symptoms is only a part of a larger picture. Treating the child without understanding the needs and status of the caregiver will only partially treat the problem and will likely not lead to lasting wellness. The approach can be compared to treating a broken bone with only pain medication without resetting the bone. If the bone does manage to heal on its own, at best the healing process will be lengthy, and the patient may have lifelong problems or deformities as a result.

Widening the definition of the patient requires a transcultural nurse's insight and discernment. Because informal kinship care families are complex and dynamic, the individuals who make up the family unit being treated as the patient may change over time. Initially it may only be the child and a single caregiver who must be considered as the patient, while later or in other situations there may be another caregiver, a birthparent, or other children who are inseparable from the greater whole. Because this method of thinking about the patient runs counter to the practice in most Western health care facilities, changes in thinking must be followed by the development of new practices.

Redefining Health

Just as the definition of the patient is broadened in this new model, the definition of health must also be expanded. This model uses a holistic definition of health which, according to *Mosby's Medical Dictionary* is "a system of comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the

[family]" (Anderson, 2002, p. 822). This holistic approach is important because each of these factors not only influence other factors but also are inseparable from one another.

Though holistic health is not a novel idea, the type of holistic health that is proposed in this model remains rare in health care practice settings. Wollumbin (2012), points out that holistic health in current practice typically takes the form of complementary or alternative therapies, which are often used in place of conventional Western medicine rather than alongside Western medicine. Although this practice leads in the direction of holistic health, it does not fully meet the definition proposed here. Wallumbin states that both the scope of practice and the end goal of holistic health care must be expanded to include the "vast array of skills and knowledge required to build economically vibrant communities of healthy, educated individuals living sustainably in harmony with each other and their broader environment" (p. 80). This idea of holistic care implies a health care system that considers all aspects of the person, including the person's environment and social situation and attempts to address and meet those needs comprehensively. The experience of informal kinship care families shows that although there may be a plethora of medical professionals, social workers, therapists, special education professionals, and legal professionals involved in the care of informal kinship care families, these professionals are disconnected. The proposed model attempts to draw these professionals together through transcultural nursing leadership and assessment rather than sending the informal kinship caregiving family out alone to try to meet needs in a disjointed manner.

Building Trusting Relationships

In order to come alongside informal kinship care families in their quest for sustained wellbeing, transcultural nurses must first build a trusting relationship with the family. As a population that has been neglected by the health care system, informal kinship care families may not trust health care professionals to understand or listen to their unique needs. The majority of informal kinship care families in the United States are African American, a cultural group that has traditionally been distrustful of the professional system and has found services to be culturally inaccessible (Hanlon, Carswell & Rose, 2007). Usually conflict initiated the need for the child to be cared for by an informal kinship caregiver rather than the birthparents, contributing to fear by the caregivers that law enforcement or child welfare agencies may intrude. They may therefore be hesitant to trust any professional system with the reality of past traumas, current instability, and ongoing custodial conflict. Many informal kinship caregivers also experience shame over their own perceived failures as caregiver, which may cause them to be cautious about opening up to professionals (Hanlon et al., 2007).

Building trust begins with taking time to listen and asking nonjudgmental questions. It also involves setting aside the professional elitism that remains dominant in the health care community. A transcultural nurse takes a place alongside the informal kinship care family rather than as a superior professional. Transcultural nurses must be prepared to provide nonjudgmental care that considers past failures of the health care system to meet this population in their place of need and the informal kinship care family's current fears of a system that will work against them rather than with them.

Description of the Model Through a Conceptual Representation

In order to more fully describe the Model of Support of the Informal Kinship Care Family and the interactions between the child, caregiver, and nurse, a series of three figures depicting the patterns of the family and nurse are shown. Figure 1 represents a child and informal kinship caregiver. The goal of the Model of Support of the Informal

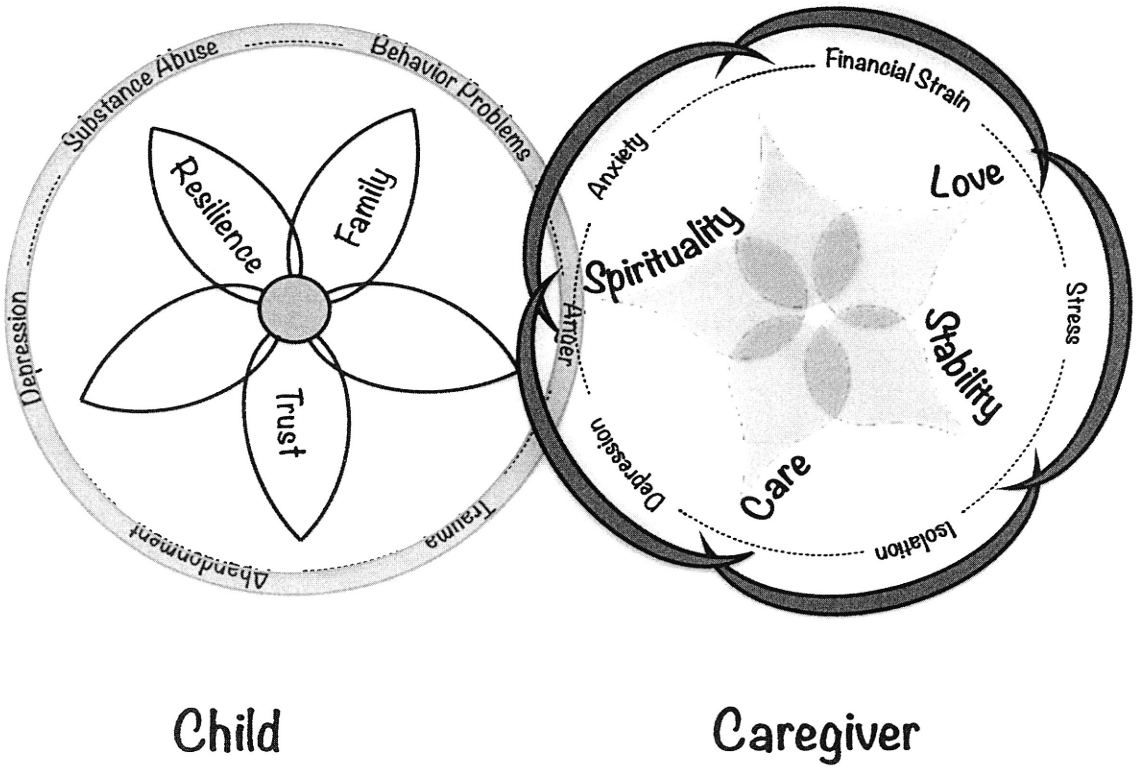

Figure 1 Model of the Child and Caregiver

Kinship Care Family is to move a child and caregiver from operating as isolated pieces to functioning in harmony as a larger whole, the family. As the figure shows, each person carries within him or her strengths but is completely encircled by negative life situations, challenges, and struggles. However the strengths are the core of the child and caregiver. Resilience is shown to describe the ability the child has to survive and adapt to the devastating life challenges that he or she inevitably encounters. This resilience is

what helps the child be well despite difficult circumstances. The child is also equipped with a family; people in the child's life who are willing to step into the role of caretakers until the birthparents are stable enough to resume their parental roles. The caregiver also has strengths that he or she is equipped with and that motivate the caretaker to assume this challenging role. While there may be a multitude of strengths, the ones represented here are love, stability, care, and spirituality. By being able and willing to accept the role of caregiver and expending personal resources to provide the child with what he or she needs physically and emotionally, the caregiver is able to provide a level of stability. The caretaker loves the child, and that love motivates the caregiver to not only take on the role of caretaker but to also put in considerable effort to ensure the child's wellbeing. The caretaker also has a feeling of care for the child that stems out of love as well as the resources to physically nurture the child. The literature indicates that many informal kinship caregivers identify their spirituality as a motivator for caring for a child as well as a source of strength for the caregiver personally (Gleeson et al., 2009). The spirituality, stability, love, and care that are intrinsic to the caregiver can provide the caregiver with meaning and purpose in the face of drastic life changes and challenges. These strengths provide a motivation that is deeper and stronger than simple obligation.

In their isolated states, child and caregiver, though equipped with impressive internal strength, are left to cope alone with the enormous challenges closing in from every direction. The child's challenges such as depression, anger, and behavior problems impact the wellbeing of the child and strain the child's ability to use his or her strengths to cope. For example, past trauma or the emotional consequences of parental abandonment or substance abuse may threaten the child's ability to trust the caregiver to

remain a source of stability. The same concept is true for the caregiver. The challenges that the caregiver faces such as stress, anxiety, depression, social isolation, and financial strain impact the caregiver's ability to display love and care for the child and maintain a stable home. In the face of these challenges, the caregiver may no longer derive the strength from their spirituality that they once were able to depend on.

As was shown, these negative influences press inward and affect the individual, but they also act as a barrier between the child and the caregiver. As the child and the caregiver attempt to connect, they are forced to confront the challenges of the other. For example, a child's issues such as anger or behavior problems meet with and exacerbate a caregiver's depression or anxiety. This contentious interaction works the other direction as well; the caregiver's stress or social isolation may conflict with the child's history of abandonment or substance abuse, leading to a recurrence of emotional or physical problems as they are forced to confront those issues again. As a caregiver attempts to bring stability, love, care, and spirituality to the child, the caregiver must first deal with his or her own challenges, and then meet the challenges of the child before the caregiver can connect with the child in a meaningful way.

In response to the isolated, conflicting patterns of child and caregiver, a transcultural nurse is represented in figure 2. Equipped with the new model of approaching informal kinship care families, the transcultural nurse holds the key concepts and values of relationship, holism, hope, and transformation.

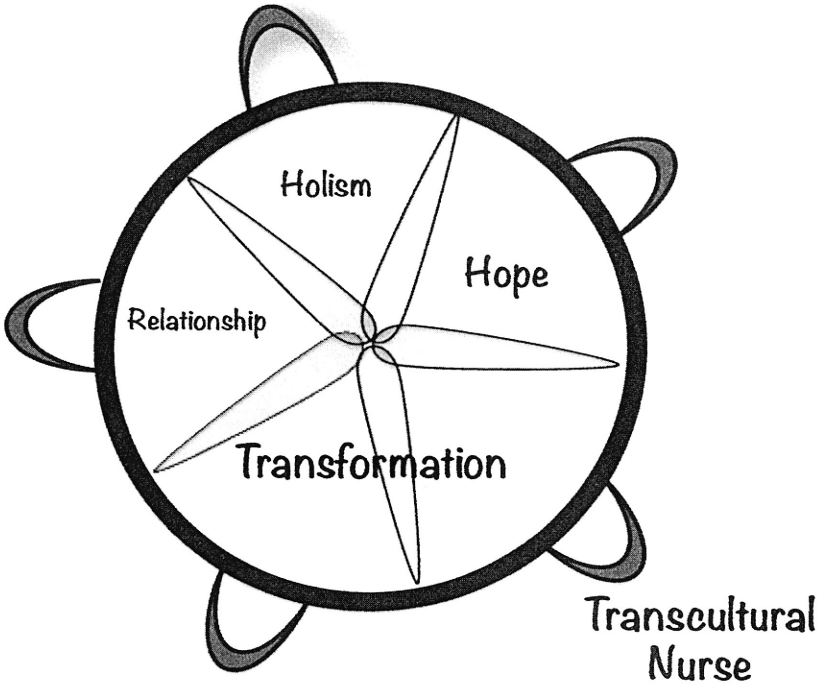

Figure 2 Model of the Transcultural Nurse

Relationship

Newman (2008) describes the relationship between a nurse and a patient as a transforming presence. She believes that it is through this relationship that the patient is able to begin to find meaning and purpose and can start the process of recognizing life patterns that must be changed in order to achieve wellness. Without the interaction and interconnectedness that relationship brings, true transformation would not occur.

Though Newman (2008) focuses on the relationship between a nurse and a patient, in this model the transformational nature of relationships is applied to the connection between the informal kinship caregiver and child as well. Mutual support, respect, and trust are the building blocks for these relationships between informal kinship care family members. The transcultural nurse's goal is to support the child and caregiver in realigning their relationship or connection so that they no longer inflame each other's

weaknesses and challenges. Figure 1 displayed how the patterns of the child and caregiver were aligned in a way that the challenges met, leading to greater dysfunction. For example, the caregiver's stress over financial strain may cause him or her to behave in a way that evokes the anger of the child or triggers an emotional response from past traumas. Using the resources available, the transcultural nurse helps the child and caregiver change their patterns of relating to one another so that they move toward a connection that adapts, adjusts, and transforms, allowing their intrinsic strengths rather than their weaknesses to interact.

Holism

A key way that a transcultural nurse can help bring the informal kinship care family from a connection of conflict into a relationship is through a holistic approach. By using the comprehensive view of the family that holism offers, the nurse is able to treat each member of the family as an individual as well as a vital piece of a larger whole. Through this approach, a transcultural nurse does not attempt to address only the physical or mental manifestations of illness, but additionally looks beneath the surface to help bring the members of the informal kinship care family to a place of wholeness and wellness whether or not there are symptoms of disease present.

Hope

A third concept that the transcultural nurse carries is hope. According to Jean Watson (2008), hope is an intrinsic process that carries people through the unknowns, crises, illness, and pain in life and is as important for healing as medical treatment. Watson also holds that hope begets hope. A nurse has hope for the informal kinship care family when they are unable to hope for themselves and in time, the hope of the nurse

becomes the hope of the family. As the transcultural nurse holds hope for the family while providing holistic and competent care, the family can begin to experience this hope for themselves. They can begin to expect that the challenges of the past will not be the challenges of the future.

Transformation

The end goal of the nursing process with the informal kinship care family is transformed individuals and a transformed family. In her Theory of Health as Expanding Consciousness, Newman (1994) defines transformation as an individualized process of gaining knowledge and personal realization that leads people into a place of critical awareness of both old and new views of themselves. The individuals then choose to integrate both of these views into a new definition of self and others, which leads to transformation. Though transformation may seem a lofty goal when asked only to help treat a physical illness or provide care for a child with psychiatric problems, it is possible. By understanding the deep challenges that informal kinship care families face and taking the time to look beneath the surface, a transcultural nurse cannot only alleviate pain and provide health care education, but can seek holistic care for the family through resources that the transcultural nurse is able to access. Once a child and caregiver begin to experience a relief of symptoms and find themselves supported through the other challenges they face, they can begin to experience hope both individually and as a family, which then leads them to a place of transformation.

Figure 3 shows the informal kinship care family transformed. As a transcultural nurse draws the family in through relationship, holistic care, and hope, they retain their

individuality but begin to function as a whole. Their strengths work together and their weaknesses fall to the background through the support of available holistic care.

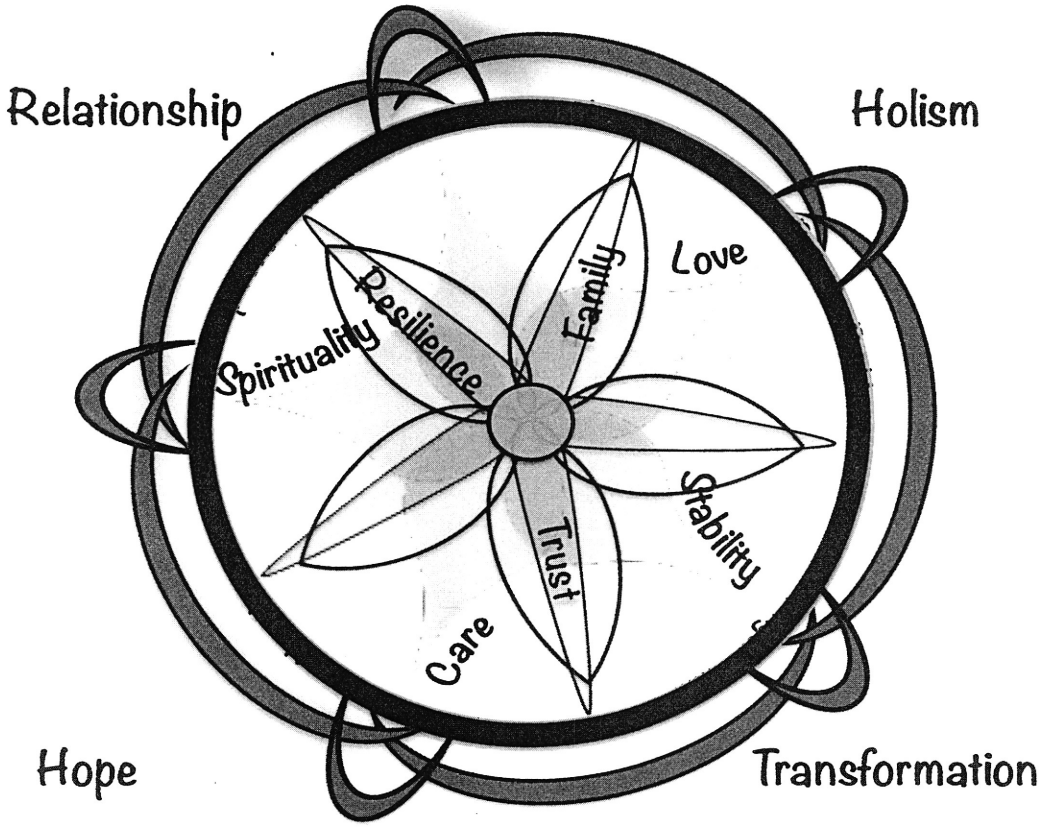

Figure 3 Model of the Transformed Informal Kinship Care Family

Support of Model Through Nursing Theory

Newman's (1994; 2008) Theory of Health as Expanding Consciousness was used to support the creation of this new model of thinking about and approaching informal kinship care families. One of the base assumptions of this theory is that health is a pattern of the whole and symptoms of disease or wellness are just one view of a larger picture. Another assumption is viewing the environment as an event, situation, or phenomenon with which a person interacts. To view these assumptions in terms of the informal kinship care family, each member has a pattern of functioning. These patterns

are represented in the models of the child and caregiver in figure 1. Each has a pattern or way of reacting to the stressors in his or her life. For children, this pattern may be that as they face the reality of abandonment by their birthparents, they face emotional turmoil that may emerge as externalized behavior problems. In the case of the caregiver, their pattern may be that as they try to provide love and care to a child, but are running into the child's pattern of anger and behavior problems, the caregiver experiences anxiety and depression. The conflict and imbalance to health that occurs indicates the need for the formation of new patterns or ways of functioning. These new patterns are formed through relationship. Through the support of the transcultural nurse and the pattern that the nurse contributes, the child and caregiver are able to change their initial conflicting patterns of being and relating to one another. As new patterns emerge through relationship with the nurse and with each other, their consciousness is expanded and they have a new level of understanding.

This proposed model relies heavily on the assumption that the physical symptoms individuals display are the result of the process of changing or maladaptive patterns within the person as a whole. A transcultural nurse then understands that high blood pressure, anxiety, depression, behavior problems, and mental illness are only a small picture of what is taking place in the whole person. Through this model, the transcultural nurse treats the physical or mental symptoms with the best options available, but also works to uncover what else may be taking place to cause the manifestation of these symptoms.

The Theory of Health as Expanding Consciousness also offers direction for the nurse in defining the goal of the nursing process. The role of the nurse offered by

Newman (1994; 2008) is to meld curing with caring in order to help people use the power and strengths they already possess in order to move to a place of better functioning and transformation. This happens through the recognition of dysfunctional patterns and the formation of new patterns of relating to the world and others. A nurse accomplishes this through relationship, which Newman calls the essence of nursing. Newman recognizes that people find themselves in the context of community and that people experience aloneness as their lifestyle changes, which creates the demand to develop new and more meaningful relationships.

Plans for Implementation

Newman's ideas and the model presented in this paper can sound very abstract, however informal kinship care families face challenges that are not at all abstract. The trauma, depression, suicide attempts, physical strain, legal battles, and financial hardship are all very real, very concrete problems that these families are forced to encounter. The goal of this model is to influence transcultural nurses to create new, concrete processes and ways to help informal kinship care families meet their needs in a way that brings them to a place of sustained wellbeing.

While there is no current plan for using this model in a widespread manner in a clinical setting, there are ways that this model can be implemented. On a small scale, discerning transcultural nurses can use this model in any practice setting. A first step would be to share the model with transcultural nurses to create awareness of this neglected population and the considerable challenges that they encounter. The problem must first be identified before health care facilities will change their practices to better support and meet the needs of informal kinship care families. Most current modes of

operation in health care facilities do not make this model practical, however a nurse familiar with the model can still use the key concepts to better support informal kinship care families. An example of this would be a transcultural nurse providing a caregiver bringing in a struggling child, with contact information for easily accessible therapy not only for the child but for the caregiver as well. It may mean having the clinic social worker visit with family on the spot rather than asking them to come back at a later time or simply giving them contact information. While this is not the type of holistic care that this model aims for, it is a step in that direction.

Perhaps the most ideal, though slightly less realistic, application of this model would be in the creation of a nursing center specifically for informal kinship care families. In this setting, it would be possible to have, through the leadership of a transcultural nurse, a safe place in the community where informal kinship care families can come to receive nonjudgmental care and resources. By having a place dedicated to these families, they would have access to professionals educated about the specific needs of this population and who work together with the newly defined family to provide comprehensive care. In this setting, a nurse would be able to ensure that these families receive the best care that scientific health care has to offer for physical and psychiatric needs while having access to resources and education regarding financial and legal problems.

Summary

Neglected and poorly understood, informal kinship care families have been left to fend for themselves in the face of constant and overwhelming hardships. Though systems within the health care community are not currently organized in a way that

promotes holistic care and sustained well-being for these families, transcultural nurses are in a position to provide leadership to change the way health care professionals think and approach informal kinship care families. By widening the definition of the patient and health to include a holistic view of the family unit, transcultural nurses take the first steps to bring about improved care to these families. Through trusting relationships, transcultural nurses bring the values of functioning relationships, holistic health care, and hope to these families with the goal of bringing them to a place of transformation.

Chapter 4: Evaluation and Reflection of the Conceptual Model

Just as any nursing intervention or change in practice requires evaluation, the appropriateness and effectiveness of the conceptual Model of Support for the Informal Kinship Care Family requires careful evaluation. As a new model based on limited research available on this neglected population, evaluation and analysis is vital for both further development of the model as well as better understanding of informal kinship care families. This evaluation and analysis will be achieved through the use of focus groups, critical analysis of the model and personal reflection by the author, as well as a brief reassessment of the theoretical framework.

Focus Groups as an Evaluation Tool

Evaluating programs can be particularly difficult for vulnerable and neglected populations because of the significant impact that cultural factors have on perceptions of health care services and meanings of health and illness (Kaiser, Barry, & Kaiser, 2002). One method found to simultaneously evaluate the effectiveness and usability of a program while discovering the perceptions of a population is focus groups (Kaiser et al., 2002; Loriz & Foster, 2001; Wyatt, Krauskopf, & Davidson, 2008). Focus groups, which could serve to evaluate a conceptual model, are carefully planned, nonthreatening discussions among a group of people who have similar experiences designed to give insight into the population's perceptions.

There are several advantages to focus groups that make this method of evaluation a good option for assessing the nursing model proposed in chapter three. The first advantage is that focus groups convey the message to diverse groups that the health care system regards their opinions as important (Kaiser et al., 2002). For neglected informal

kinship care families, conveying this message is necessary if the health care system is to provide effective care. Not only will this help build trust between the health care system and these families, it will encourage further sharing of information by informal kinship care families. There is currently a large gap in the literature regarding these families and their needs. Focus groups have the ability to not only test the effectiveness of the nursing model presented but to widen the understanding and knowledge of transcultural nurses about the dynamics of the informal kinship care family.

The second advantage of using focus groups to evaluate the Model of Support for Informal Kinship Care Families is that they are useful in not only evaluation but in further planning as well (Wyatt et al., 2008). The model presented is based on literature that is limited in breadth and depth. As such, the author needed to make assumptions about the population in the creation of the model. These gaps in knowledge contribute to a model that is in its early, unrefined stages. Focus groups are an ideal method to find out not only if the model is effective in providing support to these families but also to further develop the model. Focus groups have the potential to help move the model from a one dimensional framework to a model that is well developed and offers practical applications.

The nonthreatening nature of focus groups makes it the ideal environment for participants to communicate what works and what does not work as well and to air concerns and emotional reactions (Loriz & Foster, 2001; Wyatt et al., 2008). This method also empowers individuals by giving them a voice, providing them with a sense of responsibility, and allowing them to be active participants in their care (Loriz & Foster, 2001). All of these factors make focus groups an effective way to engage

populations that are typically difficult to reach in order to assess the quality of an intervention (Kaiser et al., 2002). While health care providers may have their own measures of quality, focus groups provide a forum for informal kinship care families to share their viewpoints regarding quality as well as their goals for what they would like to achieve.

Focus groups have been found to be effective with diverse groups of people. In fact, focus groups are believed to be an effective method for engaging and discovering the thoughts of children and adolescents because the group dynamic removes the burden from any one child to respond. The verbal format of this tool also compensates for children or adults that struggle with reading or writing (Wyatt et al., 2008). More commonly used evaluation methods such as written surveys or questionnaires would prevent children or adults who are uncomfortable reading or writing from participating.

Though the advantages of focus groups are many and well documented, there are a few disadvantages as well. A well-run focus group requires extensive planning and preparation (Wyatt et al., 2008). If the focus group is to achieve its goal, the moderator must be skilled and prepared with appropriate questions that keep the group on task without limiting or influencing the responses of the group (Wyatt et al., 2008). Considerable thought and effort needs to be expended in setting up the details of the focus group. In order to be effective, the group needs to be held in a safe and culturally accepted location and needs to be at a convenient time of day. In order to encourage participation, incentives will likely be necessary, child care may need to be provided, and issues of transportation must be considered (Kaiser et al., 2002).

Though there are challenges to holding an effective focus group, it remains an ideal means of evaluating the effectiveness of the Model of Support for Informal Kinship Care Families. Focus groups have the potential to be used at any stage of application of the model to evaluate its implementation and to inform further utilization of the model. A focus group can be held in any health care facility that has adopted the model and serves informal kinship care families. It is assumed that because families used services at a proposed health care facility previously that the location is relatively convenient. Health care facilities are also typically considered a safe location and provide facilities that can be easily adapted to holding a nonthreatening discussion. Depending on how widely the model is used with informal kinship care families, separate focus groups can be held simultaneously for adults as well as children over a certain age. By asking strategic questions, a fairly thorough evaluation of the model and practice changes can be completed in a reasonable time frame. A checklist has been provided in the appendix listing the important factors to consider when facilitating a well-planned and effective focus group.

Critical Analysis and Personal Reflection

The existing literature regarding informal kinship care families is limited. Most of the literature about this subset of families looks specifically at grandparent-led families. While grandparent informal kinship caregivers certainly have experiences in common with other informal kinship caregivers such as aunts, uncles, cousins, siblings, godparents, or family friends, grandparents likely face unique experiences as well that other informal kinship caregivers do not. They may face different challenges because of their age, the relationship with their adult child who is unable to raise their own child, or

other factors related to their stage of life. Besides looking at grandparent caregivers, the literature that was used to form the Model of Support for the Informal Kinship Care Family explored families functioning under the umbrella of a child welfare organization. While again these families would face similar challenges and experiences, it is likely that their situation would also be unique to that specific population. Formal foster care and the intervention of child welfare agencies gives families advantages and resources as well as suggests that there is something different in these families' experiences that required an outside agency to intervene. Creating a model based on limited literature, the personal experiences of the author, and informal interactions with informal kinship care families has the potential to lead to inaccurate assumptions.

While the model is based on limited literature, there are strengths to the model as well. Though the personal experiences of the author create the potential for a bias toward what she feels is most important without consideration of the wider population, her position as an informal kinship caregiver adds depth and insight that would be missing otherwise. Another strength of the model is that it attempts to fill a hole in the health care system by creating an awareness of the situation of these families and providing a starting point to further develop and provide health care services that will address their specific needs. Though the gaps in the literature affect the model, failing to create a model because of limited research would only be further ignoring an already neglected population.

From the author's personal and professional standpoint, this model both begins to fill a vacant space as well as remains open for refinement. During the process of creating this model, one of the girls that I care for as an informal kinship caregiver experienced a

particularly difficult time emotionally and took me on a painful journey with her of suicide attempts, psychiatric admissions, crippling anxiety, and explosive conflict with her biologic family. As I tried to support her while struggling to deal with my own fears, exhaustion, and stress, the lack of supportive care in the health care community for informal kinship care families was obvious, but so was the inability of the model I was creating to fully address the depth of need. My personal reflection supports my professional critical reflection; this model is limited and not yet tested, however it brings light to an issue that is largely neglected and provides a starting point for improving care and support for families like mine.

Reassessment of the Theoretical Framework

Upon reassessment of the Model of Support of the Informal Kinship Care Family, Newman's (1994) Theory of Health as Expanding Consciousness remains an appropriate choice for the theoretical framework. The abstract nature of the theory did create a challenge for the author in harnessing the abstract ideas into a usable form that compassionately and effectively addresses the needs of the informal kinship care family. Despite the challenges, Newman's focus on viewing the physical, mental, and spiritual individual as one whole pattern rather than as parts that can be divided greatly influenced this model. The focus on holistic health care and consideration of the impact of the social environment on the wellbeing of a person fits well with Newman's theory. The holistic focus as well as Newman's thoughts on patterns being an expression of health give justification for the model's attention to the interrelationships between past traumas, current challenges, and health.

The process of evaluation is vitally important for further development and improvement of any nursing model or intervention. For the Model of Support of the Informal Kinship Care Family, use of focus groups to evaluate the application of the model is an ideal way to improve the use of the model, further the development of the model, and prove to the families being cared for that their input is important. Evaluation in the clinical setting as well as a critical assessment of the development process leads to specific implications for advanced practice transcultural nurses and their role in decreasing health care disparities, which will be discussed in the next chapter.

Chapter Five: Implications, Next Steps, and Conclusion

In this increasingly diverse world, it is important that transcultural nurses take a lead role in providing culturally appropriate care in the attempt to not only provide competent health care to the populations they serve but to work to eliminate widespread health care disparities. The review of informal kinship care families displays the level of difficulty some populations have maintaining health and finding and accessing health care that responds to their varied and complex needs. The goal of the Model of Support of the Informal Kinship Care Family is to bring awareness to the situation of informal kinship care families, provide them with improved care, and move them from a place of disadvantage to a place of strength. Informal kinship care families are indeed a neglected population, but unfortunately they are just one group out of many in the United States that is poorly understood and served by the health care system. The struggles of informal kinship care families and the wider base of marginalized populations highlight implications for advanced practice transcultural nurses and their role in decreasing health care disparities.

Implications for Advanced Practice Transcultural Nursing

Perhaps the greatest implication for advanced practice transcultural nurses is the necessity for a leader and educator in the health care community. Transcultural nurses have the insight and ability to see people and the world in a different way than the majority of health care professionals. While nurses in general have long accepted a broader view of health and healing, nursing and medicine remain very scientifically driven fields. The implication for the advanced practice transcultural nurse is to be a leader in melding sound scientific knowledge with insightful care that takes into account

people and their context. It is important for transcultural nurses to not only be leaders in practice, but to educate surrounding health care professionals in the art of assessing and caring for diverse groups of people. One way this can be done is through sharing models such as the Model of Support of the Informal Kinship Care Family.

Another implication for advanced practice transcultural nurses is the call to participate in research. Though there is little research on informal kinship care families, in the personal experience of this author, there are communities in which this phenomenon is common and widespread. It is important to know who these families are, how they function, and define their needs. Without research it can be difficult to convince institutions and policy makers that there is a problem that the health care system needs to address. Research is important to not only show the reality of the problem but also to create new practices and policies that meet people in their place of need. It is important that advanced practice transcultural nurses specifically participate in this research because of the need not only for statistics and demographics, but to capture the voice and the lived experience of these families and other neglected populations. Unless the health care and research communities hear directly from these populations, in their own words, it is likely that care will continue to be given based on what health care professionals deem important, not based on the true needs of the populations receiving the care.

Implications for Decreasing Health Care Disparities

In order to reduce health care disparities it is necessary to first identify and understand the populations that are not being met by the health care system. This understanding must go beyond the type of understanding that comes from book

knowledge or clinical expertise. Health care professionals must understand the perceptions of the population as well as the broader context of the individuals, families, and communities that they serve.

The situation of informal kinship care families highlights the ability that whole groups of people have of staying off the radar of the health care community. In this paper, informal kinship care families have been talked about in terms of being a neglected population. The failure of the research and health care communities to understand or support practices that meet these families in their place of need certainly makes these families neglected. Unfortunately the majority of these families are neglected or disadvantaged before they become informal kinship care families. The little research that is available on these families informs us that the majority of these families are poor African Americans living in impoverished, violent, and drug infested neighborhoods (Grant, 2000; Sheran & Swann, 2007; Strozier & Krisman, 2007). It can perhaps be assumed that the crises that lead to children being cared for by someone other than the biologic parents are related to the challenges and dangers associated with living in disadvantaged communities. This deepens the importance of providing understanding and improved care to informal kinship care families in order to not only improve the situation of informal kinship care families but also to better serve their communities.

Next Steps

Before the Model of Support of the Informal Kinship Care Family can be used fully and effectively, better research and an increased awareness by the health care community regarding the challenges faced by informal kinship care families must be achieved. Though there is no immediate plan to put the Model of Support of the Informal

Kinship Care Families into action, it is suggested that as a next step, the model be used to help educate and inform transcultural nurses and other health care providers about the needs of informal kinship care families. Though it is difficult to find documentation related to these families and where they live, through the personal experience of the author and information shared by other informal kinship care families during the development of this model, it is known that there are communities where informal kinship care families are not rare, and are likely commonplace. Beginning to create awareness of these families and their struggles through educating the nurses who serve these communities would be a first step at improving care.

Along with creating increased awareness, it is necessary to the improvement of care to informal kinship care families to have better research regarding these families. The lack of research specific to informal kinship care families has been briefly discussed throughout this paper, and remains a barrier to fully understanding the context of informal kinship care families and their needs. A next step to the deepening of the Model of Support of the Informal Kinship Care Family and care in general to these families would be research studies specific to this population.

Conclusion

Many people face enormous difficulties that are not easily seen from the outside. These difficulties such as social conflict, poor and violent communities, depression, and anxiety impact and are impacted by the wider context of these individuals and families. Despite having the best intentions, nurses and other health professionals will continue to fail to meet the needs of these people if the health care community does not begin to gain a better understanding of the entire context of these people's lives. For neglected and

struggling populations such as informal kinship care families, a lot is at stake. Not only is the wellness of the child, caregiver, and family at stake, so is the strength and ability of these individuals and families to break free from destructive cycles or patterns such as social conflict and poverty.

In response to the broad societal impact, the overwhelming challenges documented in the literature, the frustrations verbalized by informal kinship care families during the development of this model, and the personal experiences of this author, it is vital that the health care community take action. While a model such as the Model of Support of the Informal Kinship Care Family will not address or solve every problem, challenge, and disadvantage of these families, it is the first step to accompany them into a place of greater wellness and transformation. Under the broadened definitions of patient and of health, this model places these families into a position as patients who require the attention of transcultural nurses specifically and the health care community in general. Through trusting relationships, transcultural nurses are able to encourage healthy relationships and patterns of interaction between informal kinship care family members, beginning the process of transformation. By taking into account the full context of the family and providing holistic care, transcultural nurses are able to meet these families in their place of need and provide hope in the struggle. The ultimate goal of these steps of the Model of Support of the Informal Kinship Care Family is for families to be transformed and lasting wellness to be achieved at last.

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Appendix
Focus Group Guide

- ☐ Moderator
  - Adequate knowledge of the topic
  - Demographically similar to the participants
  - Skillful in group discussions
  - Able to tactfully redirect challenging participants
  - Prepared with prewritten questions
- ☐ Assistant Moderator
  - Helps handle logistics
  - Takes notes and monitors recording equipment
  - Does not verbally participate in the discussion
  - Helps facilitate details and welcomes participants
- ☐ Participants
  - 6-10 people preferable (large enough to generate discussion but not so large that people may feel uncomfortable speaking)
  - Homogenous groups
- ☐ Recruitment of participants
  - Flyer posted in health care facility
  - Identify participants through list of families served at health care facility
  - Send personal invitations
  - Contact each participant the day before the focus group
- ☐ Pre-prepare appropriate questions
  - 8-12 questions
  - Open-ended questions- Use first to allow participants to answer however they see fit without imposing answers on them
  - Follow-up open ended questions with probing or clarifying questions to develop thoughts
  - Avoid "yes/no" questions
  - Focus questions in a general to specific direction
- ☐ Environment
  - Comfortable
  - Circle seating
  - Nonthreatening
- ☐ Incentives for participation
  - Money, coupons, gift certificates, small gifts, opportunity to win a big-ticket item in a drawing, food, opportunity to share insights, etc.

- ☐ Consider possible barriers to attendance
  - Time- consider population and adjust time to make attending more convenient
  - Transportation- consider proximity to bus line, consider providing bus or cab fare
  - Location- convenient and familiar
  - Child care- consider providing child care services for duration of the group

Suggested Outline

- ☐ 45-90 minutes total
- ☐ Warmly welcome participants, offer refreshments, ensure participants' comfort
- ☐ Introductions
  - Introduce moderator and assistant moderator
  - Introduce participants
  - Introduce topic
- ☐ Guidelines
  - There are no right or wrong answers
  - Whether agree or disagree, everyone's views will be respected equally
  - One person to speak at a time
  - Want to hear from everyone
  - Group will be recorded, but participants will be kept anonymous
- ☐ Questions/Discussion
  - Opening question
  - Allow discussion
  - Ask appropriate clarifying questions as needed
  - Ask appropriate probing questions to get depth
  - Repeat question-discussion-probe format for remaining predetermined questions
- ☐ Conclusion
  - Summarize discussion
  - Review purpose of group
  - Ask if anything was missed
  - Thank participants
  - Dismissal