

MĀLAMA NĀ MAKUA I NĀ KEIKI ME KA HĀNŌ:
NATIVE HAWAIIAN PARENTS CARING FOR THEIR
CHILDREN WITH ASTHMA

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DEDICATION

Mālama Nā Makua I Nā Keiki A Me Hānō is dedicated to *nā makua* who participated in this research as well as those who share in the same responsibilities of caring for their children with asthma. I have learned so much about how Native Hawaiian parents *mālama* or earnestly care for their children. They have my admiration, respect, and *aloha*. It is my sincere hope that this dissertation will initiate better asthma care for Native Hawaiian parents and their children.

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ABSTRACT

Background

Native Hawaiian children have the highest prevalence rate of asthma among all ethnicities in the State of Hawai‘i. Literature is limited regarding Native Hawaiian parents’ perception and experience caring for their children with asthma in the context of uncertainty. Nurses require more information and theoretical guidance to competently assist Native Hawaiian parents in asthma care.

Objective

The purpose of this study is to explore contemporary Native Hawaiian parents’ perspective and experience of caring for their children with asthma in the context of uncertainty.

Method

Descriptive qualitative approach by means of directed content analysis using focus groups was applied to this study. Focus groups were likened to “talking story,” a familiar method of sharing information among Native Hawaiians. Eight open-ended questions elicited asthma history, asthma management, and how the Hawaiian culture affects parents’ health practices. Directed content analysis applied Mishel’s Uncertainty in Illness Theory (UIT) to guide data collection, organization, and analysis.

Results

The concept analysis of uncertainty and literature review confirmed the application of the concept among multiple disciplines. Interview data were organized into the UIT constructs, categories and subcategories. New subcategories related to asthma care (lack of asthma

experience and asthma triggers) and culture (differentiation between Western therapies and complementary alternative medicine) were identified.

Parents' personal stories and accounts provided rich data. The study's findings verified that Native Hawaiian parents experience uncertainty regarding asthma care as commonly described in literature. Contextual influences including indigenous worldview and cultural values affected Native Hawaiian parents' perceptions and experiences with conventional asthma care. Unique findings involved the etiology of asthma and features of social support (*'ohana*).

Conclusion

Nurses are in a strategic position to alleviate Native Hawaiian parents' experience of uncertainty regarding asthma care. Nurses will find the application of the UIT constructive when working with Native Hawaiian parents because their unique perspectives and experiences can be better assessed and understood. As nurses become more knowledgeable about indigenous viewpoints including cultural values and preferences, they will be able to assist Native Hawaiian parents in a familiar and acceptable manner. Future implications for research, nursing practice, and policy have been provided.

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CHAPTER 1

INTRODUCTION

Chapter one presents the background of the study, statement of the problem, research purpose, and research question. The concept of interest is uncertainty. Uncertainty is experienced by most parents in the care of their chronically ill children. This is particularly true of parents of children with asthma.

In the illness experience, uncertainty has four forms: (a) ambiguity concerning the state of the illness, (b) complexity regarding treatment and system of care, (c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability of the course of the disease and prognosis. This study is concerned with the uncertainty experience Native Hawaiian parents may have regarding asthma care. What aspects of asthma care are unclear, hazy, imprecise or confusing?

The background section will present a description of the uncertainty experience of parents with children with asthma and elaborate on additional concerns Native Hawaiian parents may experience while caring for their affected children. Native Hawaiian children have the highest prevalence rate of asthma among children of all ethnicities in the State of Hawai'i. Indigenous worldview, cultural values, historical context, and effects of assimilation and acculturation may contribute to parents' experience of uncertainty regarding conventional asthma care. Research is sparse regarding Native Hawaiian parents' experience of and perspective on caring for children with asthma, particularly in the context of uncertainty.

Background

The statistical significance, extensive effects, and health disparities of childhood asthma in the United States and in the State of Hawai'i will be presented first in this section. This will

be followed by a discussion of parents' experience of caring for children with asthma, with special attention to Native Hawaiian parents.

Asthma Statistics

Asthma is one of the most prevalent chronic childhood diseases in the United States (Akinbami, 2006; Akinbami & Schoendorf, 2002, p. 1066; Laster, Holsey, Shendell, McCarthy, & Celano, 2009). Currently, 6.7 million children have asthma, representing 9.1% of children in the United States (Bloom, Cohen, & Freeman, 2009). Of this population, more boys (15%) were diagnosed with asthma than girls (11%) (Bloom, et al., 2009).

Asthma is the third leading cause of hospitalization for children (Dowd, Zajacova, & Aiello, 2009). The cost for treating asthma in children is estimated at \$3.2 billion per year (CDC, 2006a). There were approximately 4 million children who missed a cumulative total of 12.8 million school days due to an asthmatic episode (DOH, 2011b).

Health disparities exist among ethnic minorities. African Americans (Gerald et al., 2006) and Hispanic children have disproportionately high prevalence of asthma (Brim, Rudd, Funk, & Callahan, 2008; Canino et al., 2006). The National Health Interview Survey of 2007 established that non-Hispanic black children were more likely to have been diagnosed with asthma (20%) compared with Hispanic children (13%) and non-Hispanic white children (11%) (Bloom, et al., 2009). In addition, children of American Indians and Alaska Native descent are 1.3 times more likely to have asthma compared with white children (Akinbami, Moorman, Garbe, & Sondik, 2009).

Research is now demonstrating that social determinants are strongly associated with asthma (Gern et al., 2009; Williams, Sternthal, & Wright, 2009). Children in low socioeconomic families were more likely to have been diagnosed with asthma (17%) than children in families

that were of higher socioeconomic backgrounds (12%) (Bloom, et al., 2009). Children living in poverty may reside in deteriorated, violence-filled urban communities and attend inferior day care and schools (Belanger, Kielb, & Lin., 2006; Williams, et al., 2009). In their everyday environment, they are exposed to asthma triggers such as lower quality and crowded homes, polluted air and water, and noise (Liao, Morpew, Amaro, & Galant, 2006; Williams, et al., 2009). Children in low socioeconomic families have less access to city services, financial resources, and constant and stable social supports (Liao, et al., 2006; Williams, et al., 2009). Minority children and children of low socioeconomic status use urgent care or emergency room services more than preventive medical care for asthma (Kim, Kieckhefer, Greek, Joesch, & Baydar, 2009).

Hawai'i Asthma Statistics

Asthma is a major public health problem in Hawai'i (DOH, 2011b). There are more than 106,000 people affected with asthma in this state, one-third of whom are children (DOH, 2011a).

When Hawai'i was surveyed with 22 other states in 2003, Hawai'i ranked third highest in Child Lifetime Asthma Prevalence Rate (13.4%; n=39,691), and seventh in current asthma prevalence rate and numbers (8.6%; n=25,397) (CDC, 2006a, 2006b). The 2005 State of Hawai'i Department of Health (DOH) data report states males (25,144) experiencing asthma occurrences more than females (15,751) (DOH, 2007).

Child asthma status for Hawai'i for years 2005 through 2009 has ranged from 32,000 children (11%) to 37,000 children (12%) of the population (DOH, 2011a). (See *Appendix A: Table A1*) The data indicate that the percentage of children in Hawai'i with asthma is higher than the national average. The continuously high number of children with asthma demonstrates that childhood asthma is a significant health problem in the State of Hawai'i. Additionally, very

young children (0-4 years of age) with asthma constitute the highest number of patients seen in emergency rooms and subsequently hospitalized (DOH, 2011b).

Asthma episodes may be attributed to the tropical environment and year round exposure to allergens and irritants such as flowering plants, dust, mites, mold, cockroaches, and pet dander (Boyчук, Halm, et al., 2006; Chan et al., 2002). In addition, sporadic atmospheric conditions such as volcanic air pollution may contribute to asthma (DOH, 2011b).

Native Hawaiian Children with Asthma Statistics

Statewide household surveys were conducted yearly by the DOH to identify the number of children with current asthma by ethnicity. Ethnicity was self-reported by the respondent. In 2008, 12,591 children (17.1%) of Native Hawaiian ethnicity had asthma (DOH, 2010a). Native Hawaiian children have had a high prevalence of asthma compared to children of other ethnicities according to trended data (DOH, 2010a; Krupitsky, Reyes-Salvail, Baker, & Pobutsky, 2009). (See *Appendix A*: Table A2, Table A3, Table A4, Table A5)

The large numbers of Hawaiian children with asthma indicate a great disparity in health within the State of Hawai'i. Therefore, nurses need to better understand how Native Hawaiian parents are managing asthma care in order to determine if modified approaches would be more beneficial in supporting these parents.

Asthma Care

Asthma experts are clear about what information and skills need to be learned for asthma management and control in the home (Akinbami, et al., 2009). The primary resource for asthma care management is the National Asthma Education and Prevention Program (NAEPP) that provides physicians and health care providers with clinical practice guidelines on the treatment of asthma (Lurie, Mitchell, & Malveaux, 2009). According to the NAEPP, each patient should

have a written Asthma Action Plan that guides the patient and family on basic asthma care, what to do during episodic asthma exacerbations, when to call the health care provider, and when to seek emergency care (Piper, Elder, Glover, & Baek, 2008).

In order to attain and maintain asthma control, parents are required to learn a multitude of tasks and concepts such as how to recognize asthma symptoms (Grad et al., 2009; Wu, Glauber, Gay, & Lieu, 2009), administer proper medication (Broder, Gutierrez, Chang, Meddis, & Schatz, 2010), protect their children against allergens (Salo, Sever, & Zeldin, 2009), offer proper nutrition, supervise exercise and strenuous activities, and maintain regular medical care (Stephenson, Quimbo, & Gutierrez, 2010). Additionally, depending on disease severity, patient and parents may be involved with a variety of health care professionals and settings (i.e. emergency room, hospital, primary care) (Koenig, 2007), requiring further skills.

Parents with Children with Asthma

Although standard asthma care is specific and effective, many parents have difficulty managing their child's asthma because of the multifaceted nature of the disease and treatment. Asthma is a complex chronic disease of the airways that is characterized by variable and recurring symptoms involving fluctuating areas of airflow obstruction (Gruchalla et al., 2009). Asthma symptoms may be difficult to recognize, allowing the disease to follow an unpredictable and inconsistent course that may become life-threatening (Gruchalla, et al., 2009).

Nearly all parents with children with asthma undergo uneven and complex processes of recognizing initial asthmatic symptoms, understanding the diagnosis, learning and implementing a treatment regimen, and finally, transferring their knowledge and skill to the affected child (Coffey, 2006). The development of parental competency takes years and happens at varying

levels and intensities of uncertainty, particularly when new and unfamiliar events occur (Buford, 2004).

Native Hawaiian Parents with Children with Asthma

Literature is limited about Native Hawaiian parents and their care of children with asthma. Tse and Palakiko (2004) conducted a community based participatory research project to learn about the perspective of Native Hawaiian parents and family members regarding asthma and its treatment. Their research found that parents relied heavily on emergency asthma medication and depended on physician approval for care. Many were not aware of the seriousness of the chronic disease and when their child was having difficulty with the illness.

According to health care providers statewide, parents including Native Hawaiian parents, require more support and assistance in the following areas: (a) education, (b) disease management, (c) prevention, (d) healthcare, and (e) support (Hirokawa & Kishaba, 2005). They specifically need more education regarding “signs/symptoms/definition of asthma, appropriate care-seeking, asthma triggers and risk factors, proper medication use and compliance, proper method of medication delivery, appropriate use of peak flow meters, asthma action plans, and treatment guidelines” (Hirokawa & Kishaba, 2005, p. 71).

Although parents statewide, including Native Hawaiian parents, require more education in standard asthma care, nurses need to recognize that conventional asthma health education and teaching strategies may not be effective for ethnic minorities (Handelman, Rich, Bridgemohan, & Schneider, 2004). Medical and nursing literature provide evidence that parents’ personal and cultural health care beliefs strongly influence actual health practices, use of home remedies, receptivity to the use of medicine, and access of the health care system (Canino, et al., 2006; Palafox, Buenconsejo-Lum, Kaanoi, & Yamada, 2001). Furthermore, literature validates the

importance and impact of provider-parent collaboration in securing successful asthma care (Ring et al., 2011; Tse & Palakiko, 2006; Tse, Palakiko, & Texeira, 2005).

As indigenous people of the Hawaiian islands (known as *Kānaka Maoli*), Native Hawaiian parents' personal and cultural health care beliefs need to be understood by nurses (Blaisdell, 1982; Bushnell, 1993). In addition, Native Hawaiian parents may experience added dimensions of uncertainty about conventional asthma care. Experiences unique to Native Hawaiians such as indigenous worldview, cultural values, history, and assimilation and acculturation of Western and Asian cultures may influence their perspective. Moreover, preference for complementary and alternative medicine (CAM) in the form of traditional indigenous healing practices should also be considered along with conventional medical care of asthma (see *Appendix B: Native Hawaiian Worldview and Cultural Considerations* and *Appendix C: Historical Context*).

Indigenous Worldview. The fundamental worldview of the Native Hawaiian revolves around their spiritual belief system. This system establishes their origin and positioning as Native Hawaiians, as well as their relationship with powerful and omnipresent spiritual deities (Hewett, Alailima, Kamakea-Ohelo, & Mann, 2001; Mokuau, Hishinuma, & Nishimura, 2001). Health, illness, island gods and goddesses, family relationships, and healing traditions are tightly intertwined for Native Hawaiians (Hewett et al., 2001; Mokuau et al., 2001). Therefore, understanding the indigenous worldview regarding health, illness, and treatment of a condition such as asthma is fundamental to health care management.

Western medicine, on the other hand, adheres to a positivistic and mechanical philosophical orientation that approaches health and illness in a focused, objective, and discrete manner (Tse, et al., 2005). Native Hawaiian parents may not understand or appreciate such an

orientation (Broad & Allison, 2002; Palafox, et al., 2001). They may prefer their health care providers to put more effort and time towards understanding their entire personal and family circumstances (Kaholokula, Saito, Mau, Latimer, & Seto, 2008).

Western knowledge in the form of the scientific method, “germ theory,” and the nature of allergens and allergen control are not fundamental concepts in the Hawaiian tradition as the basis for illness (Houser, 2008). Therefore, it may be difficult for Native Hawaiians to accept the notion that traditional sources of power (*mana*) such as sections of land (*‘āina* or *kuleana*), plants, flowers, and trees (Oneha, 2001) are allergens and considered dangerous to their asthmatic child. Native Hawaiian uncertainty about the veracity and trustworthiness of conventional asthma treatment and the requisite avoidance of allergens may be related to a lack of understanding, as well as a reluctance to accept specific aspects of Western medical care.

Cultural Values and Concepts. Cultural values are recognized and respected when providing acceptable care to Native Hawaiian parents and their children (Consortium, 1985). Hawaiian values of helping (*kōkua*), caring (*mālama*), and being responsible (*kuleana*) are carried out with *aloha* (affection, compassion) to the weak or ill individual (Chun, 2008b). Being *pono* (living correctly) and maintaining harmonious (*lōkahi*) relationships are more critical to the well-being of Native Hawaiians than material or personal gain (Chun, 2006b).

The *‘ohana* (extended family, kinship) is the most vital concept in Hawaiian culture because it explains and maintains traditional Hawaiian interpersonal relationships (Pukui, Haertig, & Lee, 1972). Respecting family elders (*kūpuna*) and teachers of Hawaiian arts and skills (*kumu*) is integral to the value of *‘ohana*. Other associated values include affiliation and close bonds between peers and social networks (Consortium, 1985), and the importance of the

group rather than individual needs (H. McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993).

Unfortunately, Western health care systems not only fail to incorporate important Hawaiian values but may institute policies and procedures that contribute to the uncertainty experience for Native Hawaiian parents. Challenges inherent in the current health care system for Native Hawaiians include unfamiliar health care personnel, a confusing multi-level health care system, adherence to rigid time schedules, attention to cost rather than relationship, separation from family (*'ohana*) during hospitalization (Bushnell, 1993), and non-inclusion of family members (*'ohana*) when discussing health matters (Bushnell, 1993; McDermott, Tseng, & Marezki, 1980).

Nurses, therefore, should be acutely aware of cultural values that influence the promotion of health and disease management. Conversely, attitudes and behaviors that may contribute to uncertainty experiences ought to be avoided. For example, intergenerational relationships may be sources of support as well as conflict in families (Hewett, et al., 2001; Kana'iaupuni, Malone, & Ishibashi, 2005). If there are any differences in opinion about treatment, such as Western medical treatment versus indigenous health practices recommended by a family elder or healer, serious discord may be experienced within the family. Harmony (*lōkahi*) and doing what is proper and good (*pono*) are crucial cultural values that may be damaged by conflicting health care beliefs and practices (Chang, 2001). Therefore, it is essential to learn about the healing practices advocated by involved family members before implementing a nursing plan of care.

Although the *'ohana* is the most important social structure in Hawaiian culture, this social system may be less strong, cohesive and supportive in current society. Challenges for Native Hawaiian families include high single-parent households; conflict within families as

indicated by reports of abuse and neglect; disproportionately high rates of substance abuse, arrests, and incarcerations (Kana'iaupuni, et al., 2005). Nurses must recognize the need to assess the inter-relationship and functioning of each *'ohana* in order to provide client-specific nursing care.

Historical Context. Contemporary Native Hawaiians may be more cautious and suspicious in their dealings with foreigners because of their history of betrayal and suffering (Kuykendall, 1938, 1953, 1967; McDermott, et al., 1980; Rezendes, 1996). With the passing of 80% of the native population due to infectious disease and loss of land ownership, Hawaiian domination waned by the end of the nineteenth century (Blaisdell, 1982). Conversely, Western influence expanded and slowly dictated a new way of life that included a ban against Hawaiian religion, prohibitions on speaking or writing the Hawaiian language in schools and businesses, promotion of a cash base economy, implementation of Western style education and land ownership (Hoomanawanui, 2004; Kame'eleihiwa, 1992; Silva, 2004). Eventually, the Hawaiian monarchy was overthrown in 1893, and Hawai'i was annexed to the United States in 1898 (Kame'eleihiwa, 1992; McDermott et al., 1980).

Historical trauma may affect the outlook of Native Hawaiians on foreigners (*haole*) and their healing practices (Bushnell, 1993). Who is considered a credible healing authority by Native Hawaiian parents is a question that requires assessment by nurses today.

In addition, consideration should be given to the effectiveness of existing health education strategies. If health education material such as written Asthma Action Plans is assessed by Native Hawaiian parents as unclear and delivered in a manner that is unfamiliar, a negative perception of the health care system will be reinforced (Bushnell, 1993; McDermott, et al., 1980).

Assimilation and Acculturation. Today, most Native Hawaiians possess two or more ethnic heritages that influence the make-up of their health care beliefs and practices. This is due to early Western and Asian immigration, and close community contact that promoted intermarriages by Hawaiian royalty and commoners alike (Kanahele, 1986; Kuykendall, 1938, 1953, 1967; Linnea, 1999). As sugar cultivation transformed the Hawaiian nation's economic system, foreign laborers and plantation workers were secured from Portugal, China, Japan, the Philippines, and Korea (Kuykendall, 1938, 1953, 1967). Intermarriages and close networking among the different ethnic groups provided a "melting pot" experience where the use of various words, foods, traditions, and home remedies were adopted across ethnic lines (Chun, 1986; Corum, 1985). Thus, the health beliefs and practices of Native Hawaiians may be complicated due to one or more of these immigrant heritages.

Complementary and Alternative Medicine. Nurses need to be sensitive to the possibility that parents are utilizing CAM including traditional or indigenous native healing practices (Ortiz, Shields, Clauson, & Clay, 2007). Children with asthma on regular conventional therapy like short-acting beta-adrenergic agonists, corticosteroids, and leukotriene modifiers may also be receiving CAM products administered by their parents.

The reported national rates of CAM use by children with asthma ranged from 33%- 89% (Braganza, Ozuah, & Sharif, 2003; Li & Brown, 2009; Sidora - Arcoleo, Yoos, McMullen, & Kitzman, 2007; Slader, Reddel, Jenkins, Armour, & Bosnic-Anticevich, 2006). Many indigenous people and ethnic minorities continue to rely on their traditional healing practices (Freidin & Timmermans, 2008; Mazur, DeYbarrondo, Miller, & Colasurdo, 2001).

Parents may rely on CAM because they are seeking a cure for asthma as well as alternative natural methods that are without long term side effects (Ko, Lee, Munoz-Furlong, Li, & Sicherer, 2006). Some CAM therapies may have some added benefit for affected children such as Vitamin A (Kumar, Batra, & Arora, 2002), Vitamin C (Harik-Khan, Muller, & Wise, 2004), and fish oil (omega-3 & omega-6 fatty acids) (Gyorik & Brutsche, 2004). Breathing exercises and relaxation are also of assistance (Gyorik & Brutsche, 2004).

However, serious harm may occur if children are given herbal compounds in addition, to prescribed asthma medications. For example, certain herbal remedies (e.g. ephedra) may be harmful when taken together with prescribed asthmatic medication (e.g. albuterol) (Lanski, Greenwald, Perkins, & Simon, 2003). Most Native Hawaiian herbal remedies listed in *Appendix D: Lā'au lapa'au* (Herbal Medicines) have unknown therapeutic results or side effects.

Literature is unclear regarding contemporary Native Hawaiian parents' perception toward standard asthma care and traditional healing practices such as *lā'au lapa'au*. It is thought, however, that a great many Native Hawaiian parents may prefer and actually implement traditional healing practices because of their desire to re-establish an indigenous identity (McCubbin & Marsella, 2009). On the other hand, there are many Native Hawaiian parents who reportedly rely on standard asthma treatment and physicians for asthma instruction (Tse & Palakiko, 2004).

Asthma Programs for Native Hawaiians. Currently, there is a lack of stable and sufficient number of on-going asthma intervention and educational programs throughout Hawai'i. Availability of programs fluctuates based on obtainable funding and participation of active leaders and volunteers. Unfortunately, only a few asthma programs identified in literature integrate Hawaiian culture and values. In one of the most notable of recent initiatives, the Office

of Hawaiian Affairs (OHA) awarded a grant of \$28,843 to the American Lung Association of Hawai'i for its *Maopopo Oli Hano* (Understanding Asthma) program. This is a three-part asthma education program specifically for Native Hawaiians on the islands of O'ahu, Maui, and Hawai'i involving school age children with asthma, school personnel, and parents (ALA, 2011).

Additionally, the Childhood Rural Asthma Project (CRA Project), funded by CDC through the DOH, encourages community health centers (CHC) to hire community health workers to go into the homes of underserved asthmatic patients and families. This in-home asthma education is specifically focused on eliminating triggers in the home environment (DOH, 2010b). The three CHC engaged in the CRA Project currently are Waianae Coast Comprehensive Health Center, Ko'olauloa Community Health and Wellness Center, and West Hawai'i Community Health Center. Additional funding will be required by the end of 2011 in order for these projects to continue. (See *Appendix E: Asthma Initiatives and Programs in Hawai'i*)

The Center for Native and Pacific Health Disparities Research, Department of Native Hawaiian Health, John A. Burns School of Medicine developed a diabetes training project to improve the knowledge of community health workers serving Native Hawaiian clients. This is an example of a culturally based intervention project. The cultural components chosen to promote awareness included such elements as the Hawaiian language, positive culture-based examples, food preferences, photos, and Pacific island graphics. A key feature in the program was the development of relationships between instructor and participants that encouraged the acknowledgment of personal, geographic, and familial connections (Look, Baumhofer, Ng-Osorio, Furubayashi, & Kimata, 2008). The study successfully demonstrated increased diabetes

knowledge within the client group and satisfaction with the program on the part of the urban group of community health workers.

These cultural components implemented by the diabetes project can be utilized for an on-going asthma control program. Additionally, effective teaching strategies include verbal step-by-step instruction, integration of Hawaiian proverbs and personal stories, active demonstration and observation, and experiential manipulation of supplies and equipment (Chun, 2006b; Kana'iaupuni, et al., 2005). Foremost is the development of collaborative relationships between nurse and Native Hawaiian parents based on mutual respect and understanding. Such a relationship would facilitate the bridging of any potential knowledge transfer gaps.

Statement of Problem

A great ethnic disparity among children with asthma exists in the State of Hawai'i. Native Hawaiian children have significantly higher current asthma prevalence (18%) compared to the percentage of children of other ethnicities (Krupitsky, et al., 2009). The exceedingly high numbers of Native Hawaiian children with asthma has been a serious and continuous public health concern.

In order to achieve asthma control, Native Hawaiian parents must successfully learn how to manage their children's overall asthma care. Therefore, parents require on-going assistance and education about the disease condition, etiology, signs and symptoms, asthma triggers (Warman, Silver, & Wood, 2009), treatment modalities, and when to seek regular health care and urgent care (Christman, 1990; Jurgens, 2006).

Unfortunately, the number of statewide initiatives and programs has been insufficient and time-limited to large numbers of affected Native Hawaiian families (Hirokawa & Kishaba, 2005). New approaches must be considered in order to successfully assist and support Native

Hawaiian parents caring for their children with asthma particularly in regard to the evident health disparity that exists (Canino et al., 2009).

Native Hawaiians as indigenous people should have a “voice” in the development of asthma programs and be given an opportunity to express what type of support and assistance would be of true benefit to them. Contextual influences including worldview, cultural values, history, and assimilation and acculturation factors may affect Native Hawaiian parents’ perceptions and experiences with conventional asthma care. New research is needed to provide contextual information in efforts to understand contemporary Native Hawaiian parents’ perspectives and experiences with asthma care.

By uncovering parents’ perspective of asthma care, nurses will be able to modify their practice to become more culturally sensitive and effective (Houser, 2008). Nurses will understand how to be more supportive of Native Hawaiian parents caring for their children with asthma. Additionally, new knowledge will be incorporated into the design of future educational materials and intervention programs (Houser, 2008). The realization of enriched parent-directed programs to improve the well-being of Native Hawaiian children with asthma and their families is a compelling goal.

Purpose

The purpose of this study is to explore Native Hawaiian parents’ perspective and experience of caring for their children with asthma within the context of uncertainty.

Research Question

What are Native Hawaiian parents’ perspective and experience of caring for their children with asthma in the context of uncertainty?

Summary

Chapter 1 provided the background of the study by establishing asthma as a national and statewide chronic childhood disease. Statistics demonstrated a continuous disparity of childhood asthma among Native Hawaiian children compared to children of other ethnicities in the State. Asthma care is complicated and requires multifaceted and continuous caretaking skills by parents.

Literature is sparse regarding Native Hawaiian parents' perspective and experience of asthma care. In light of their indigenous worldview, cultural values, history, assimilation and acculturation with Western culture, Native Hawaiian parents may experience further dimensions of uncertainty regarding conventional asthma care. The purpose of the research is to explore Native Hawaiian parents' perspective and experience of asthma care in the context of uncertainty.

CHAPTER 2

LITERATURE REVIEW

Chapter 2 consists of the literature review and the concept analysis of uncertainty. Definitions, associated concepts, antecedents, attributes, consequences, theoretical frameworks, and implications of the concept of uncertainty with regard for nursing will be presented.

Definition and Purpose of Concept Analysis: Uncertainty

Concept is defined by Rodgers and Knafl to be “cognitive in nature “ and comprised of “attributes abstracted from reality, expressed in some form and utilized for some common purpose” (Rodgers & Knafl, 2000, p. 33). Additionally, “concepts are more than words or mental images alone” and may involve a “family resemblance” of “cluster concepts” (Rodgers & Knafl, 2000, p. 33).

The purpose of the concept analysis of uncertainty is to clarify the current status of the concept by identifying what is known about it, examining its evolutionary background through a literature review, and determining the similarities and differences between disciplines when it is applied. Frameworks and theories of uncertainty as well as instruments that measure uncertainty will be examined in order to gain a broad understanding of the concept.

Method of Concept Analysis: Uncertainty

Beth Rodgers’ evolutionary perspective was selected to analyze the concept of uncertainty because its worldview and assumptions are aligned with the nature of uncertainty (Rodgers & Knafl, 2000). The study of uncertainty as a process is fundamental to its analysis, and the evolutionary view adopts the naturalistic paradigm which recognizes that concepts are evolving as well as interacting with multiple contextual realities. The evolutionary perspective seeks to understand concepts and believes that concepts are “fuzzy,” “dynamic,” open to stimuli,

and may change within different contexts (Rodgers & Knafl, 2000, p. 77). The primary components of the evolutionary approach to concept analysis are as follows:

1. Identify the concept of interest and associated expressions.
2. Identify and select the appropriate realm (setting and sample) for data collection.
3. Collect relevant data to identify:
 - a. Attributes of concepts
 - b. Contextual basis of the concept, including interdisciplinary, socio-cultural, and temporal (antecedent and consequential occurrences) variations.
4. Analyze data pertaining to the characteristics of the concept.
5. Identify an exemplar of the concept.
6. Identify implications and hypothesis for further development of the concept (Rodgers & Knafl, 2000, p. 85).

Identifying Concept of Interest and Associated Expressions

The concept of uncertainty is being explored because uncertainty is oftentimes identified as a negative experience and proved to be a barrier to successful asthma management. In accordance with the evolutionary perspective, the goal of this analysis is a pragmatic understanding of the concept so that nurses are able to help decrease the uncertainty experience and improve parents' competence in managing their children's asthma successfully. Most parents encounter uncertainty in three phases during their children's initial asthmatic episodes: diagnostic, treatment and home management, and when new and unfamiliar events occur.

Concepts related to uncertainty are risk and probability. Uncertainty is encountered when an outcome of a new event is unknown. Risk is defined as a situation with known probabilities that are less than 1.0 (Cohen, 1993). Cohen goes on to explain that all human actions are taken

under risk because consequences of behavior cannot be known with absolute certainty. Parents of a child with a life-threatening illness take “risks” when they make critical decisions for their child’s well-being. Optimally, when decisions are made under risk, the problem is clearly defined, and options and statistical probabilities of the consequences are presented. For example, one father created a multi-factorial model of risk and survival to plot his son’s prognosis in order to decrease the uncertainty about his future (Cohen, 1993).

Probability also provides a quantifiable measure or chance that an event will occur, i.e. 50% probability that a child of a parent with an inherited disease will also have the affected gene. Uncertainty, on the other hand, does not offer a statistically reliable form of prediction that an event will occur or provide any quantifiable measure that an outcome will occur.

Setting and Sample for Data Collection

The initial search on Pub Med’s electronic database for the keyword “uncertainty” was limited to the period from 1960 and 2007. The search resulted in 19,661 items (articles). The search in the Cumulative Index to Nursing & Allied Health Literature (CINAHL) electronic database for the keyword “uncertainty” resulted in 702 items published from 1982 to 2007.

Due to the large number of items which contained “uncertainty” as a key term, the list of items was narrowed to studies that focused only on “uncertainty in illness” in the four disciplines of sociology, psychology, medicine and nursing. These four disciplines were chosen because they published the highest number of articles regarding the concept and because they studied various contexts of uncertainty during the illness experience.

Rodgers has specified that either 30 items are the minimum needed to demonstrate a credible analysis for each discipline, or 20 percent of the total number of articles per discipline, whichever is greater (Rodgers & Knafl, 2000). After reviewing abstracts and identifying

commonalities in the usage of the concept of uncertainty in illness, a total of 82 items in the disciplines of sociology, psychology, medicine and nursing were selected for final review. The following numbers of items in each discipline were selected: nursing (n=46), medicine (n=23), sociology (n=8), and psychology (n=5).

An additional literature search was conducted in the disciplines of sociology, psychology, medicine, and nursing published in English using Pub Med and *Cumulative Index to Nursing and Allied Health Literature* (CINAHL) from 1980 to 2007. This search specified theory and the conceptual framework of uncertainty. Key search terms used were “theory,” “framework,” “uncertainty,” and “uncertainty in illness.” The exclusion criteria comprised articles that identified uncertainty as one construct or component within the framework. Research that involved mathematical probability designs was also excluded because its utilitarian value would be limited for most practicing nurses.

Sociology and psychology did not have any conceptual framework or theory of uncertainty in the disciplines’ literature. Twelve articles in the other two fields were selected for initial review, but only four of these described a conceptual framework of uncertainty or a theory of uncertainty and were consequently accepted for final analysis. The articles included one framework in medicine, two frameworks in nursing, and one middle-range theory in nursing.

Collecting and Managing the Data

After the samples were selected, the literature was retrieved using the University of Hawai‘i-Mānoa Library Electronic Online Resources. The abstracts were initially scanned in order to obtain a general background of each discipline’s perspective and then read carefully for appropriate inclusion in tables for each discipline.

Tables were constructed to keep notes about each item related to the concept, specifically the definition, antecedents, attributes, implication of findings, and samples studied. Tables were constructed and divided into sets of notes by disciplines: sociology, psychology, medicine and nursing. Notes were maintained for all methodological decisions that were made throughout the investigation as well as drafts of thoughts, perceptions, and major themes as data collection and analysis developed.

Contextual Basis of Concept: Interdisciplinary

Analysis was first conducted by identifying the definition of uncertainty, antecedents, attributes, and clinical implications (if applicable) for each discipline. Subsequently, agreement and differences between disciplines regarding the characteristics (definition, antecedents, attributes, and clinical implications) were noted, as well as the common themes surrounding uncertainty in all the disciplines.

Sociology. Eight items (articles) involving uncertainty in illness were found in the sociology literature. The concept of uncertainty in sociology is primarily associated with medicine and medical decision-making (F. Davis, 1960; Griffiths, Green, & Bendelow, 2006; Haram, 2005; Lankshear, Ettore, & Mason, 2005; McIntosh, 1974, 1976; Nettleton, 2006; Rafalovich, 2005).

The literature review revealed that the earliest research on the concept of uncertainty was conducted in 1960 by Fred Davis, a sociologist. He studied the uncertainty that physicians and parents of children stricken with poliomyelitis experienced from the pre-diagnostic phase to re-entry into the community (F. Davis, 1960). A high level of (real) uncertainty existed initially when the child is diagnosed with poliomyelitis because the extent of damage sustained is unknown. However, in time the medical team is able to determine the probable extent of the

prognosis. Davis discovered that health care providers prolonged the uncertainty experience for parents because they were uncomfortable with exposing the probable disability to parents who might react emotionally and require additional attention.

Definitions of uncertainty in sociology included risk (Haram, 2005; Lankshear, et al., 2005), clinical uncertainty versus functional uncertainty (F. Davis, 1960; McIntosh, 1976), medical uncertainty (Griffiths, et al., 2006), opposite of absolute certain about disease or outcome (McIntosh, 1976), and unclear diagnosis (Nettleton, 2006).

Antecedents of uncertainty in sociology were the following: unknown prognosis of cancer (McIntosh, 1974, 1976); difficulty to make medical decision due to multiple and unknown factors, i.e. labor and delivery cases (Lankshear, et al., 2005); inability to accurately predict outcomes due to unknown damage, i.e. damage to spinal nerves (F. Davis, 1960; McIntosh, 1976); unknown HIV status of partner (Haram, 2005); unknown diagnosis (Nettleton, 2006); not knowing the etiology of attention deficit hyperactivity disorder in order to determine correct treatment (Rafalovich, 2005); and women's confidence in physician's treatment plan (Griffiths, et al., 2006).

Attributes of uncertainty in sociology were related to clinical uncertainty (real difficulties in determining diagnosis and prognosis) versus functional uncertainty (management of patient) (F. Davis, 1960; Griffiths, et al., 2006); anxiety (McIntosh, 1976), powerlessness (Griffiths et al, 2006; Haram, 2005), marked skepticism (Rafalovich, 2005), and medical dilemmas (McIntosh, 1974).

Implications of uncertainty were seen in Nettleton's study of patients who suffered from medically unexplained symptoms (MUS) that included living a life of uncertainty which is

permanent and irreducible; having an undiagnosed syndrome of pain that is chaotic with no clear beginning or onset of symptoms (Nettleton, 2006).

If the cause of a condition (like ADHD) was uncertain, physicians were ambivalent about selecting the correct treatment plan (such as Ritalin medication) (Rafalovich, 2005). If physicians delayed in identifying the prognosis, patient and family experienced prolonged uncertainty (F. Davis, 1960). When physicians were uncertain about the diagnosis or prognostic outcome, their communication with the patient and family was affected. Physicians sometimes offered either very little or too much information. Their explanations consequently, were considered ineffective and were sometimes communicated at inappropriate times (McIntosh, 1974, 1976). Other conditions were equally involved in producing uncertainty. The implications of unknown HIV status not only affected individuals, it also affected entire communities, i.e. Northern Tanzania (Haram, 2005). In a reversal role, however, McIntosh (1976) found cancer patients preferred uncertainty about the disease status because it gave them hope.

Psychology. In psychology, there were five articles involving the concept of uncertainty in illness. Definitions for uncertainty in the discipline of psychology included risk (Braithwaite, Sutton, & Steggle, 2002); unpredictability (McNulty, Livneh, & Wilson, 2004); and ambiguity (White et al., 2005). Three of the five articles (L. Johnson, Zautra, & Davis, 2006; McNulty, et al., 2004; White, et al., 2005) referred to Mishel's definition of uncertainty as the "inability to determine the meaning of illness related events that occur in situations where the decision maker is unable to assign definite values to objects and events and/or unable to accurately predict outcomes because sufficient cues are lacking" (Mishel, 1990, p. 256).

Antecedents of uncertainty involved questionable risk for genetic condition (Braithwaite, et al., 2002); absence of precise etiology for disease; erratic and unpredictable symptomatology

of multiple sclerosis (McNulty, et al., 2004) and juvenile rheumatic diseases (White, et al., 2005); vulnerability; and patient care during hospitalization and discharge to home (Hunt & Smith, 2004).

Attributes of uncertainty found in psychological literature were related to patients' and families' experience during illness. They included ambiguity and unpredictability (McNulty, et al., 2004); emotional distress (White, et al., 2005); emotional strain, stress, powerlessness complex, and caregiver stress (Hunt & Smith, 2004); cognitive stressors and the sense of loss of control (Johnson et al., 2006). Other attributes of uncertainty were described as intolerance or tolerance of ambiguity, such as in the questionable transference of genetic conditions (Braithwaite, et al., 2002).

Implications of uncertainty in psychological literature were related to the experience of having a disease. When a disease has no organic cause, uncertainty becomes a cognitive stressor, and individuals experienced a loss of control as well as changed perception of their illness over time (Johnson et al., 2006).

The implications or repercussions of the uncertainties surrounding multiple sclerosis (MS) are related to the unpredictable and variable symptomology of relapses and exacerbations. Patients experienced fatigue, sexual dysfunction, social isolation, role strain, and fear of symptom exacerbation despite adherence to medical regimen (McNulty, et al., 2004). McNulty (2004) found that spirituality lessened the impact of uncertainty on patients with MS. This patient group was composed of adults. Uncertainty was also identified as a stressor for children with Juvenile Rheumatoid Arthritis (JRA) and perceived as a contributor to their negative perceptions of their illness (White, et al., 2005). According to White (2005) children experienced increase emotional distress, like depression, when uncertainty was heightened. The

child's depressed symptoms affected parental distress (White, et al., 2005). Implications for this association resulted in improved efforts to deal more effectively with inconsistencies. These efforts included attention to child and parent psychological adjustment, disease knowledge, and self care.

One study found that individuals' attitude toward uncertainty was useful in predicting health behavior and preference for genetic testing. Cancer patients who had a more negative attitude toward uncertainty were more likely to undergo genetic testing (Braithwaite, et al., 2002). In contrast, patients who were able to tolerate ambiguity were uninterested in predictive genetic testing (Braithwaite, et al., 2002).

Hunt and Smith (2004) identified three themes common to stroke victims and their relatives through their phenomenological study: uncertainty, personal impact, and strength of relationships. Patients and relatives share the same uncertainties during hospitalization and re-entry home, and all required adjustment assistance.

Medicine. Twenty-three references were identified in the discipline of medicine regarding the concept of uncertainty in illness. The definitions of uncertainty in medicine included the following: unknown (Keyserling et al., 2003; Launer, 2005; Perlman et al., 1991; Reich, Olmsted, & van Puymbroeck, 2006; Tait, Voepel-Lewis, & Malviya, 2003), not knowing the future or prognosis (Boman, Viksten, Kogner, & Samuelsson, 2004; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005); not sure, no quantifiable reason, not exact, unclear, not precise (Caro, Getsios, El-Hadi, Payne, & O'Brien, 2005; Caro et al., 2005; Launer, 2005; Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005; Perlman, et al., 1991; Sarnat & Holguin, 2007; Scher, Bigal, & Lipton, 2005); incomplete (Michaels & Monforton, 2005); unaware (Fried & O'Leary, 2006); risk (Baldwin et al., 2005); degree or proportion of

certainty versus uncertainty; lack of security (Baldwin, et al., 2005); inability to predict (Avner & Baker, 2002); questionable reliability (Faraone, Biederman, & Zimmerman, 2005); event cannot be adequately defined or categorized because lack of information, no cognitive structure is formed (Flemme et al., 2005); and worry and anxiety (Shearer & Gordon, 2006).

Antecedents to the uncertainty experience in medicine included a number of factors such as the lack of information so that an event could not be categorized or defined (Caro, Getsios, El-Hadi, et al., 2005; Caro, Getsios, Payne, et al., 2005; Flemme, et al., 2005); difficulty determining the validity of subjective reports (Faraone, et al., 2005); difficulty interpreting meaning or significance of signs and symptoms of disease; inability to predict extent and prognosis of illness or disability (Avner & Baker, 2002; Baldwin, et al., 2005; J. Clark, Bokhour, Inui, Silliman, & Talcott, 2003; Keyserling, et al., 2003; Lefebvre, et al., 2005; Lenhard, et al., 2005; Perlman, et al., 1991; Schroeder et al., 2005); how to select appropriate interventions (El-Sadr et al., 2000; Faraone, et al., 2005; Lefebvre, et al., 2005); and the nature of co-morbidity upon illness or mixed factors (Sarnat & Holguin, 2007; Scher, et al., 2005; Shearer & Gordon, 2006). The uncertainty experience for young physicians revolve around the absence of health care team support in community settings resulting in the lack of continuous observation by nurses, and easy access to tests and other professional opinion (Illing et al., 2003).

Antecedents of uncertainty for patients and their families included not knowing future harm, disease related illnesses, complications, and concern about childcare in the absence of a parent (Boman, et al., 2004; Flemme, et al., 2005; Fried & O'Leary, 2006; Reich, Johnson, Zautra, & Davis, 2006; Reich, Olmsted, et al., 2006). Parents experienced uncertainty related to surgery for their child and participation in clinical trials due to poor reading ability, insufficient

information about surgery, and poor understanding of the importance of the event (Tait, et al., 2003).

In order to improve the air quality for asthmatic patients, one study attempted to determine the causal agents or air pollution that affected air quality. However, the investigation was unsuccessful because it was difficult to determine specific causal agents. Air quality was attributed to a combination of multiple environmental factors that could not be clearly identified (Sarnat & Holguin, 2007).

Attributes of uncertainty in the discipline of medicine were related to features of the clinical decision making process. Uncertainty attributes in the discipline of medicine were identified as anxiousness, persistent anxiety, or worry (Baldwin, et al., 2005; J. Clark, et al., 2003; Lenhard, et al., 2005); unknown cause or outcome of disease (Avner & Baker, 2002; Baldwin, et al., 2005; Boman, et al., 2004; Caro, Getsios, El-Hadi, et al., 2005; Caro, Getsios, Payne, et al., 2005; Truog, Christ, Browning, & Meyer, 2006), imprecision (Harrell & Bradley, 2009); hazy understanding (Lefebvre, et al., 2005); not proven scientifically, or incomplete proof (Michaels & Monforton, 2005); lack of control (Shearer & Gordon, 2006); high perceived risk or low risk (Tait, et al., 2003); and risk aversion and insecurity (Baldwin, et al., 2005).

The implications of uncertainty in the medical literature related to the medical decision-making process and behaviors physicians exhibited when they were uncertain about the diagnosis or outcome of disease conditions. Some practitioners tended to avoid decision-making situations (Baldwin, et al., 2005; Boman, et al., 2004; Elkington, White, Higgs, & Pettinari, 2001). Some physicians prescribed antibiotics for unconfirmed or unspecified infection while waiting for laboratory results (Keyserling, et al., 2003). Some physicians decided upon more intensive monitoring if they were uncertain about the diagnosis, as in the case of pediatric

patients with fever (Avner & Baker, 2002) or the progression of a disease such as bronchiolitis (Baldwin, et al., 2005). When physicians were uncertain about acute cough and respiratory tract infection in young children, they asked parents to return the child for a recheck and prescribed antibiotics (Hay & Wilson, 2002). In the case of diagnostic uncertainty, further diagnostic actions were taken to obtain more information (Caro, Getsios, El-Hadi, et al., 2005; Schroeder, et al., 2005).

When a physician was uncertain about a health concern, the patient and family were affected. Some practitioners had difficulty establishing meaningful relations with affected family members of seriously ill patients (Lefebvre, et al., 2005). When the medical team was uncertain about the prognosis of seriously ill or injured patient such as in the case of traumatic brain injury, they might deliver a hazy and vague projection to the family (Lefebvre, et al., 2005). An early study of parents' neonatal intensive care experience with the health care team found that physician uncertainty in providing information was significantly associated with severity of illness (Perlman, et al., 1991). Literature also uncovered physician uncertainty about whether to reveal the whole truth of a life-threatening disease such as cancer (Yaniv, 2000) or chronic obstructive pulmonary disease (Elkington, et al., 2001) to the patient and family. Therefore, physicians required training and assistance in developing open communication with the patient and family regarding complex medical conditions and possible poor prognosis (Truog, et al., 2006).

The quality of life was lower for patients who had life-threatening conditions, i.e. cardiac arrhythmia, because continuous uncertainty encompassed all areas of life and influenced their daily routines and activities (Flemme, et al., 2005). It was also discovered that some older patients with cancer, congestive heart failure or chronic obstructive pulmonary disease were

essentially unaware of the terminal nature of the disease (Fried & O'Leary, 2006). One article, however, proposed that worrying was a short-term effective response to uncertainty and contributed to vigilance, preparedness, and the sense that overall risk was controlled (Shearer & Gordon, 2006).

Being definite about the etiology, diagnostic procedures, and treatment for chronic diseases and disabilities may be unfeasible. In such situations, some parents experienced long term effects of uncertainty and repeatedly throughout their life (Lenhard, et al., 2005). They felt anxious, guilty and carried emotional burden regarding the affected child's condition as well as the possible risk for siblings to develop the condition (Lenhard, et al., 2005).

On the other hand, Michaels and Monforton (2005) cited the delay of 2 to 4 years before drug manufacturers placed warning on aspirin containers to caution against administering aspirin to children because of developing Reye Syndrome. Although uncertainties surrounded the adverse effects of aspirin, they recommended acting on the knowledge that was available and placing warning labels in order to prevent unnecessary disease.

Clinical decision analysis (CDA) framework was a rigorous and systematic approach to decision making (Schwartz & Griffin, 1986; Weinstein & Fineberg, 1980). CDA proposed that clinical decision analysis begin by identifying different parts and juncture points of the problem. The physician was guided through a series of steps based on available data and probabilities (Weinstein & Fineberg, 1980). Then careful judgment was made while considering available data, options and probable outcomes. Schematic diagrams of treatment options at separate juncture points of the illness trajectory were examples of this framework.

The primary purpose of the CDA framework was to offer a better method of organizing data and support successful decision making. It could not predict events. The framework

appeared logical and useful because it provided a method by which to manage large amounts of data and structuring points of mandatory decision making, thereby decreasing uncertainty.

Nursing. There were 46 references in the nursing literature regarding uncertainty in illness. The definition of uncertainty in this discipline included the following: unknowing, incongruence between what one knows about symptoms or illness and outcome; unknowable future (MacDonald, 1996); being unprepared for an experience (Charleston & Happell, 2005); vague and unclear (Christman, 1990); risk and ambiguity (Jacobs, 2000); not knowing what to do (Trollvik & Severinsson, 2004); inability to determine the meaning of illness-related events (Flattery, Pinson, Savage, & Salyer, 2005; McCormick, Naimark, & Tate, 2006; Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006); and unpredictability (Pelletier-Hibbert & Sohi, 2001).

Antecedents to uncertainty experienced by patients and families primarily revolved around conditions such as the unpredictability of exacerbations and side effects of prescribed medication (Maltby, Kristjanson, & Coleman, 2003); unknown course of disease (Flattery, et al., 2005); future outcome (S. Lee, Lee, Rankin, Alkon, & Weiss, 2005; Wonghongkul, et al., 2006); what to do when child experienced respiratory distress (Trollvik & Severinsson, 2004); capabilities if patient had prostate cancer (Germino et al., 1998); concurrent illness and fear of recurrence of cancer (Lee, 2006; Mast, 1998); waiting for treatment or transplant (McCormick, et al., 2006; Pelletier-Hibbert & Sohi, 2001); lack of information (Twinn, 2006); outcome of high risk pregnancy (Giurgescu, Penckofer, Maurer, & Bryant, 2006); what and how a child with cancer or congenital heart disease will suffer from the disease and treatment, chances of survival, quality of life and future functional abilities (Cohen & Martinson, 1988; Dean, McClement, Bond, Daeninck, & Nelson, 2005; Santacroce, 2002; Sparacino et al., 1997); psychosocial

adjustment while undergoing therapy for cancer (Christman, 1990; Germino, et al., 1998); lack of confidence in parenting (Maltby, et al., 2003); and difficulty sensing and determining symptoms of heart failure (Jurgens, 2006).

Additionally, antecedents of uncertainty for patients and their families were related to their interaction and relationship with the health care team. They included such conditions as communication with providers (Maltby, et al., 2003); mistrust (MacDonald, 1996; Twinn, 2006); and inconsistent decision-making by health care providers (French, 2006). Immigrant families also experienced uncertainty during hospitalization because they were unaccustomed to the American culture and health care system (Lee, et al., 2005). The complex health care environment and interaction with many nurses such as in the intensive care unit contributed to the uncertainty experience for parents of seriously ill children (Coyne, 1995).

In the nursing literature, attributes to uncertainty were primarily associated with disease, treatment, and prognostic process. Attributes included the following: feeling overwhelmed, “groping in the dark”, harrowing experiences, “living in chaos”, becoming disillusioned, fearing outcomes (Horner, 1997, p. 658); a “heightened sense of vulnerability” that is accompanied by a “compelling need to know the unknowable future”, confusion, “murky” (MacDonald, 1996, p. 56); fear, feelings of helplessness, continuous strain, insecurity, vulnerability (Santacroce, 2002; Trollvik & Severinsson, 2004); very intense anxiety and distress (Giurgescu, et al., 2006; Twinn, 2006); psychological distress (Giurgescu, et al., 2006); threat, anxiety, pressure (Kagan & Kigli-Shemesh, 2005); symptom distress (Mast, 1998; McCormick, et al., 2006); temporality, danger, hazard, probability (Jacobs, 2000); changeability of uncertainty (Pelletier-Hibbert & Sohi, 2001); stress appraisal consisting of feelings of harm, threat and challenges (Wonghongkul, et al.,

2006); loss of personal control (Mast, 1995); and less hope and reduced optimism (Germino, et al., 1998).

Uncertainty evokes emotions that can be positive or threatening depending on the anticipated outcome (Hilton, 1994). McCormick (2006) studied patients awaiting coronary artery bypass surgery and found that they experienced uncertainty as a danger and opportunity simultaneously. They perceived that they were given a “second chance” at life if granted the cardiac surgery. Although uncertainty was ambiguous, it offered hope to those with terminal illness (Cohen & Martinson, 1988).

Uncertainty impacted quality of life. Cohen (1993) completed a longitudinal study of children with cancer and their families. These families experienced “sustained uncertainty” which became a part of everyday life (Cohen, 1993, p. 77). Daily routines changed due to unpredictable events as did personal relationships. Values were altered, expectations suspended, and beliefs changed (Cohen, 1993).

The nursing literature contained references to reactionary or coping behaviors by patients and families during periods of uncertainty. Parents became “vigilant” caretakers; “nurturer-comforter” to patient; requested help and information from the health care provider (MacDonald, 1996, p. 56); made accommodations in order to adapt to everyday life; developed coping strategies (Trollvik & Severinsson, 2004); relied on prayer and avoidance (Giurgescu, et al., 2006); and adopted the practice of creating experiences to keep as memories, used humor, sought support and spirituality (Flattery, et al., 2005). With reference to the efficacy of spiritual beliefs, African American men with prostate cancer did not experience fluctuating levels of uncertainty due to social support and belief in God; and their tendency to accept problems as part of life (Germino, et al., 1998).

Some research found that uncertainty and symptom severity were positively related to adjustment problems throughout treatment (Charleston & Happell, 2005; Germino, et al., 1998; Jacobs, 2000; Y. Lee, 2006). For example, the combination of uncertainty and increased pain was related to difficulty coping with fibromyalgia symptoms (Jacobs, 2000). High uncertainty, in general, was related to high emotional distress, anxiety, and depression (Thorne, 1993).

Families with chronic disease observed that the unknown was more difficult to manage because the unknown contributed to fearfulness (Cohen, 1993). Mishel (1990), on the other hand, believed that the outcome of the uncertainty experience could be twofold: patients and families could develop a positive attitude and probabilistic thinking by creating a new sense of order; or they could focus on emotionally distressing thoughts connected to aversive events which would eventually lead to post traumatic distress syndrome disorder (PTSD).

In order to mitigate the uncertainty experience for patients and families, a number of nursing actions were identified. These actions included developing trusting relationships with clients and offering effective health education (Wallace, 2005); assessing the level of understanding about the illness, sources of stress/uncertainty, and the impact illness has on family (Pelletier-Hibbert & Sohi, 2001); advocating for patients, coordinating care, and avoiding transmission of conflicting information (MacDonald, 1996; Santacroce, 2002); interpreting symptoms (Christman, 1990; Jurgens, 2006); clarifying the care-giving role between nursing staff and parent for a critically ill child; assessing whether a parent is willing and able to learn care (Coyne, 1995); preparing mentally ill patients for changes in milieu or physical location (Kagan & Kigli-Shemesh, 2005); assisting patients and families to negotiate a complex health care system and increasing the patient's control and level of functioning (Lee, 2006); providing more support to immigrant families (Lee et al., 2005); helping clients to focus on what was

currently certain and engaging in health promotion behaviors that can affect positive outcomes (Santacroce & Lee, 2006); and assessing the underlying influence of culture on beliefs and actions before intervening (Twinn, 2006).

The review of nursing literature identified two frameworks of uncertainty and one middle-range theory of uncertainty in this discipline. The first framework focuses on diabetic adult patients. The second one is about parents with children with asthma. Mishel's middle range nursing theory will be presented in the exemplar section.

The aim of one study by Nyhlin (1990) in Sweden was to understand the experience of diabetic patients facing long term complications by using the grounded theory method. The study found that, over time, diabetic patients progressed through three distinct coping stages: (1) "Coming to Terms," (2) "Keeping Going," and (3) "Making Sense" (Nyhlin, 1990, p. 1021). The research uncovered actions and attitudes that patients developed to overcome or modulate the uncertainty experience, such as learning how to make practical adjustments in daily life, learning the rules of the health care system, actively searching for information and advice, and creating positive meaning and attitudes toward illness and complications.

Buford's (2004) grounded theory research focused on parents caring for their asthmatic children. A theoretical model entitled Theoretical Model for Parent-Child Transfer of Asthma Responsibility was developed from this study. Parents experienced three stages: 1) not understanding the diagnosis, 2) learning and becoming competent in asthma management, and 3) transferring their knowledge to the child.

This model reflected two major objectives: a) parental role attainment and competency and b) self care by the child. The model promoted a positive “can do” attitude for both the parent and child and recognized the importance of family structure, childrearing style, health beliefs, etc. (Canino et al., 2006) from a system’s point of view.

Mishel was the foremost researcher of the concept of uncertainty and developed a middle-range nursing theory of uncertainty, Uncertainty in Illness Theory (UIT) (Mishel, 1988, 1990; Mishel & Braden 1988). There were four stages in the model: 1) antecedents generating uncertainty; 2) appraisal of uncertainty as a danger (inference) or opportunity (illusion); 3) coping efforts to reduce uncertainty or to maintain uncertainty depending on the perception of the uncertainty event; 4) and state of adaptation. (See *Appendix F: Uncertainty in Illness Theory*) In addition, to the theory, Mishel developed the only instrument for the measurement of uncertainty. (See *Appendix G: Measurements of Uncertainty*)

Analyze Data Regarding the Characteristics of the Concept

Similarities and differences regarding the characteristics of the concept of uncertainty among the four disciplines will be discussed in this section (Rodgers & Knafl, 2000). The definitions, antecedents, attributes and implications of the concept of uncertainty are considered characteristics of the concept.

“Unclear” or lack of clarity was a common definition of uncertainty among three disciplines of sociology, medicine and nursing. “Risk and unpredictable/inability to predict” were also common definitions among the discipline of psychology, medicine, and nursing. “Not sure” was a common definition in both psychology and medicine literature. Medicine and nursing had common definitions such as “unknown, not knowing, and unknowable.” Articles in psychology (3), medicine (2) and nursing (2) adopted Mishel’s (1988) definition of uncertainty.

Antecedents of uncertainty from sociology, psychology, medicine and nursing disciplines were all related to an unfamiliar event or unknown clinical diagnosis with unknown implications and outcome. In the sociology literature, the antecedents of uncertainty consisted of unknown diagnosis and unpredictable prognosis by physicians. Antecedents of uncertainty in the discipline of psychology were related to patients' concern for health risks and the unpredictability of disease processes.

In the discipline of medicine, antecedents were more specific and took on the form of insufficient or unrecognizable objective data (signs, physical assessment, and diagnostic tests) and subjective data (symptoms). Lack of understanding (regarding disease processes, appropriate treatment, and prognosis) functioned as an antecedent of uncertainty for the medical profession.

In the discipline of nursing, uncertainty was related to the patient's perspective of the illness experience. There were four antecedents to uncertainty: ambiguity concerning the state of the illness; complexity of the treatment and system of care; lack of information about the diagnosis and seriousness of the illness; and inability to predict the course of the disease and prognosis. Additionally, antecedents of uncertainty for patients in the nursing literature included patient/family's mistrust of health care providers and the necessity of negotiating complex clinical facilities.

There were no attributes of uncertainty common to the four disciplines. In the three disciplines of sociology, medicine and nursing, the only common attribute was "anxiety" or "being anxious." "Loss of control", "emotional strain", "stress", and "stressful" were common attributes of uncertainty identified in psychology, medicine and nursing literature. "Ambivalence" or "ambiguity" was found in both sociology and psychology literature.

“Insecure” or “insecurity” attributes of uncertainty were found in sociology and nursing literature.

In the discipline of medicine, attributes of uncertainty were related to diagnostic and prognostic limitations. Nursing literature identified the following attributes of uncertainty as related to the patient’s illness experience: feelings of helplessness, stress, continuous strain, and insecurity; and being afraid. Additionally, attributes found in the nursing literature reflected the patient and family’s heightened sense of vulnerability, feeling of threat, and possible harm due to the lack of information about the disease and prognosis.

The four disciplines of sociology, psychology, medicine and nursing literature concentrated on understanding or decreasing the uncertainty experience (implication). Sociologists, psychologists and nurse researchers, in particular, engaged in numerous exploratory studies to understand what and how patients and family members were experiencing when faced with chronic and life threatening diseases.

When physicians encountered uncertainty in clinical decision-making, they took further action by protecting the patient through hospitalization or by ordering additional diagnostic tests. An implication of uncertainty, however, for the medical profession was to delay, withhold, or be vague in explaining the diagnosis or prognosis to the patient. A sense of urgency in medical research toward confirming the effectiveness of selected therapies was noted (El-Sadr, et al., 2000; Keyserling, et al., 2003; Wang, Lin, Chang, Lin, & Hou, 2004).

In addition, a literature search for frameworks and theories of uncertainty in illness was conducted in the four disciplines of sociology, psychology, medicine and nursing. The sociology and psychology literature did not contain any frameworks or theories of uncertainty in illness. The discipline of medicine, however, proposed the clinical decisions analysis (CDA) framework

that offered a rigorous and systematic approach to medical decision making in order to decrease clinical uncertainty (Schwartz & Griffin, 1986; Weinstein & Fineberg, 1980).

The nursing literature offered two grounded theory studies regarding the experience of uncertainty for diabetic patients in Sweden (Nyhlin, 1990) and families caring for their children with asthma (Buford, 2004). Although the findings of neither study were not generalizable due to the limited nature of the methodology, new knowledge about the uncertainty experience for two specific client populations was assembled. Mishel's UIT was the only theory identified in the extensive literature review of four disciplines.

Exemplar of the Concept: Application of the Uncertainty in Illness Theory

One of the last major activities of the evolutionary approach to concept analysis is the identification of an exemplar of the concept. Mishel's theory of uncertainty, Uncertainty in Illness Theory (UIT), serves as an exemplar of a viable and valuable framework to assist nurses in the complex care of asthma.

Theories, particularly middle-range ones, are advantageous to nursing practice because they describe phenomena, explain how things work, predict results, and/or prescribe interventions (Walker & Avant, 2011). Mishel's UIT may be applied to the nursing care of parents caring for their asthmatic child (Meleis, 2005; Mishel, 1990; Walker & Avant, 2011). (See Figure 1)

Antecedents of uncertainty in the Stimuli Frame consist of the categories of Symptom Pattern, Event Familiarity and Event Congruency (Mishel & Braden, 1988). Uncertainty is experienced when any of these categories are affected. Referring to Symptom Pattern category, parents with children with asthma may experience uncertainty because symptoms of the disease are difficult to recognize and follow an unpredictable and inconsistent course. Clinical

manifestations of asthma are varied and may consist of difficulty breathing, wheezing, and/or coughing (Hockenberry & Wilson, 2007). The course of the illness may be inconsistent: symptom free periods, acute episodes, and continuous pattern of symptoms. Parents may have particular difficulty recognizing when very young children are having an asthmatic episode because of their inability to communicate their symptoms. Parents will need to become familiar with unspecific signs including irritability, restlessness, poor sleep pattern, and anorexia. In addition, parents must be alert to older children's generalized complaints associated with asthma such as having a headache, being tired, or feeling tightness in the chest (Hockenberry & Wilson, 2007).

Event Familiarity category refers to parents' familiarity or lack of familiarity recognizing the variable symptom patterns of asthma as well as the treatment required for specific signs and symptoms. In addition, Event Familiarity category refers to being accustomed to the various health care environments available for asthmatic children such as primary care, emergency room, hospital, and emergency medical services (Mishel, 1988).

The Event Congruency category relates to an expected event that is not realized such as is the case when a treatment does not produce a change in symptoms or produce a cure (Mishel & Braden, 1988). An Event Congruency dilemma occurs for a parent after administering bronchodilator medication to their child and the wheezing continues.

The Structure Provider Frame consists of modulating factors that may lessen or heighten the uncertainty experience. Credible authority, social support, and education are factors that may lessen the uncertainty experience or contribute to uncertainty. The Structure Provider categories may include positive relationships with a credible authority and helpful social support to decrease the uncertainty experience for patients (Mishel, 1990). Conversely, if the medical

authority or social support is perceived to be untrustworthy or unsupportive, then the uncertainty experience may be heightened for the parent. Health education is known to improve parental understanding and competence in asthma care (Boyчук, DeMesa, et al., 2006; Buford, 2004; Trollvik & Severinsson, 2005). However, if the teaching strategy is complicated or unfamiliar to the parent, uncertainty will not be diminished, but reinforced. The Education category also consists of the parents' level of education. Those with less than high school education demonstrate higher levels of uncertainty regarding complex home asthma management (Mishel, 1988). Therefore, it is critical to complete an assessment of the learner's needs as well as their preferred learning style before health education is delivered.

The appraisal of uncertainty as a danger (inference) or opportunity (illusion) is labeled the Appraisal Frame. Do parents perceive the disease and treatment to be one of "danger" to the well-being of the individual and family? For some parents, the disease may be considered an "opportunity" to facilitate the development of character and to strengthen the family unit (Mishel, 1990).

The Coping Mobilizing Frame describes coping behaviors. Coping may be the administration of medication when asthma symptoms are observed. Engaging in regular exercise, eating nutrition meals, and sleeping adequately are examples of effective coping behaviors for both parents and affected children.

Finally, the Adaptation Frame is the state of adaptation that parents have achieved in asthma management. How are parents adapting to their responsibilities of asthma management? Are the children's asthma symptoms well controlled? Frequent visits to the emergency room due to asthma exacerbations may be an indication that positive adaptation has not been achieved. The outcome of positive adaptation is the transference of asthma care responsibilities from

parent to affected child (Buford, 2004). Answers to these questions will assist the nurse to formulate an individual plan of care for clients experiencing uncertainty while caring for their children with asthma.

Figure 1. Model of Perceived Uncertainty in Illness

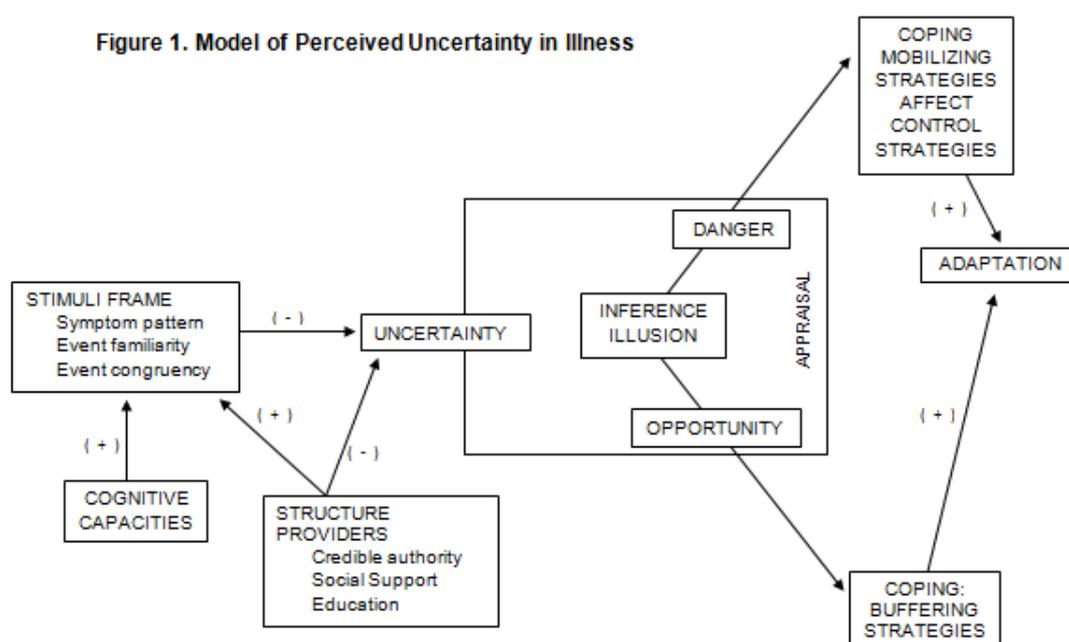


Figure 1. From "Uncertainty in Illness," by M. Mishel, 1988. *Image: Journal of Nursing Scholarship*, 20, p.226. Copyright 1988 by M. Mishel. Reprinted with written permission from author.

Summary

Chapter 2 presented the literature review and concept analysis of uncertainty as guided by the evolutionary method of analysis. A systematic review was conducted among multiple disciplines including sociology, psychology, medicine and nursing. In the literature review, one common definition could not be found by all four disciplines. It was discovered that three disciplines including sociology, medicine and nursing agreed that lack of clarity (“unclear”) led to uncertainty. Risk and unpredictable/inability to predict were also common definitions among the discipline of psychology, medicine, and nursing. All four disciplines agreed that antecedents of an unfamiliar event or unknown clinical diagnosis were marked by unknown implications and outcome.

The concept has evolved such that the literature within the four disciplines studied now associates the attributes of uncertainty with negative emotional experiences such as stress, anxiety, fear, worry, and distress. One major implication of the concept of uncertainty appears to be related to the disciplines’ attempts to understand the uncertainty experience by the patient, family, or involved health care team member (if applicable). A second major implication is the enormous attention and effort invested towards decreasing the uncertainty experience for the patient, family, and/or health care provider.

CHAPTER 3

METHODOLOGY

Chapter 3 presents the research methodology selected for this study exploring the perspective and experience of Native Hawaiians caring for their children with asthma in the context of uncertainty. The chapter will include the discussion of the methodology selection and a descriptive qualitative research approach of directed content analysis using focus groups. The protection of human rights, setting, sample selection, data collection, data analysis, and actions to be taken to ensure rigor will also be discussed in this chapter.

Methodology Selection

The purpose of this study is to explore contemporary Native Hawaiian parents' perspective and experience of caring for their children with asthma in the context of uncertainty. Descriptive qualitative approach is appropriate when investigating the perspectives of individuals, particularly those who are members of ethnic minorities (Kagawa-Singer, 2000) or indigenous peoples (Mokuau, Browne, Choy, & Braun, 2008; Struthers, Hodge, Geishirt-Cantrell, & De Cora, 2003). Characteristics common to both the qualitative approach and the Native Hawaiian worldview include concurrence with the naturalistic paradigm; acceptance of a broad and holistic worldview; and the importance of the relationship between participant and researcher (Burns & Grove, 2011). Additionally, the qualitative approach recognizes that context influences the experience (Loiselle, Profetto-McGrath, Polit, & Beck, 2007). Contextual influences particularly significant to Native Hawaiians include the influence of family, "sense of place" (Oneha, 2001, p. 308) and affiliative relationships. Moreover, qualitative data collection (e.g. observation, interview, narration) is congruent with the Native Hawaiian oral tradition of transmitting knowledge (Chun, 2006a).

Another consideration is the incompatibility of quantitative research to the study of ethnic minorities and vulnerable populations (Yancey, Ortega, & Kumanyika, 2006). Multidimensional quantitative analysis, particularly of discrete factors, will be ill-suited to both this particular mode of research and to its goals (Handelman, et al., 2004). While possible, the process of transforming subjective experiences into discrete and quantifiable data is complicated and may involve the construction of measuring instruments (Burns & Grove, 2011). Instruments, however, limit the extent and nature of respondents' answers because items/options are discrete, quantified, and ultimately controlled by the researcher (Loiselle, et al., 2007). Concepts or variables in quantitative research may not be understood, experienced, or considered important by ethnic minority populations (Loiselle, et al., 2007; Yancey, et al., 2006). In addition, lack of English proficiency on the part of the respondents may negate the results of the instrument findings. Literature has indicated that minority research subjects are unwilling to participate and continue in quantitative research primarily due to distrust of investigators, negative attitudes toward scientific and medical professions, psychosocial issues, logistics, disinterest in health topics, and religious beliefs (Yancey, et al., 2006).

Qualitative research was determined to be the most appropriate method to utilize for the understanding of contemporary Native Hawaiian parents' perspectives and experiences. As the intention of the study was exploratory, the research design required the following features: (a) able to obtain as many perspectives and experiences as possible within a limited time frame, (b) facilitate the gathering of sufficient data, (c) be acceptable to the indigenous research participants, and (d) specifically related to parents' perspectives and experiences in asthma disease management.

A number of traditional qualitative research designs were considered for this exploratory study: phenomenology, ethnography, and grounded theory (Denzin & Lincoln, 2011). Initially, phenomenology was thought to be appropriate because of its use of personal narratives to gain empathetic understanding of varied experiences (Bernard & Ryan, 2010). However, phenomenology utilizes one-to-one interview to gather data; and data collection is limited to a narrow focus of interest. Native Hawaiian parents may not feel comfortable being solely interviewed by an outside researcher (Tsark & Braun, 2004). Ethnography was also considered to be beneficial to the study because it allows subjects to speak freely about their experiences. While this may have been a possible selection, the aim to learn multiple aspects of the disease management experience may not have been met given the allotted time frame to conduct the research. Finally, the grounded theory method was considered in obtaining a variety of perspectives and experiences, however, deriving a theory to define data and explain relationships did not serve the purpose of this initial inquiry (Denzin & Lincoln, 2011). A descriptive qualitative approach was finally determined to be the most appropriate research design for this study of Native Hawaiian parents.

Research Design

Descriptive qualitative approach by means of directed content analysis using focus groups was applied to this study. Directed content analysis is a research method that is used to validate an existing theory and extend the applicability of a theory to new situations or groups of subjects (Hsieh & Shannon, 2005). The components of study are identified and defined by the theory and used to guide the collection, organization, and interpretation of new text data. In addition, the theory is able to explain the relationship between components and predict outcomes (Hsieh & Shannon).

Directed content analysis approach for this study was selected for several reasons (Hsieh & Shannon, 2005). Because literature regarding Native Hawaiian parents' experience caring for children with asthma was sparse and previous research limited, utilizing a theoretical guide for data collection and analysis ensured appropriate organization, collection of relevant data, and interpretation of findings. Theories, particularly middle-range ones, are advantageous to nursing practice (AHRQ, 2007; Doane & Varcoe, 2005). They are scientifically-based and describe phenomena, explain how things work, predict results, and prescribe interventions (Walker & Avant, 2011).

Further, if data collection and analysis were performed without a theoretical guide, it may have been difficult to determine if the newly acquired data was *trustworthy* (Hsieh & Shannon, 2005). This difficulty was due to the exploratory nature of the study. The unfamiliar nature of the subject matter and limited scope of data collection may have yielded results that may have been challenging to interpret properly if theoretical guidance was not provided (Hsieh & Shannon, 2005).

The qualitative research approach provided Native Hawaiian parents the opportunity to freely express their thoughts, opinions, and feelings in their own words (Houser, 2008). However, data collection without specific purpose, structure, and organization may not have been efficient, reliable, or straightforward to analyze (Groleau, Young, & Kirmayer, 2006). A theoretical framework was needed to guide the research because objective guidance based on scientific knowledge was especially important when caring for vulnerable populations (Canino, et al., 2009). Furthermore, evidence-based knowledge and sensitivity were required when working with indigenous people (Lucas, Michalopoulou, Falzarano, Menon, & Cunningham, 2008).

Various theoretical frameworks sensitive to indigenous groups and ethnic minorities were considered for the research including the explanatory models and conceptual model of asthma disparities. The scope of the explanatory model that is concerned with understanding health behaviors, health beliefs, and meaning of illness was considered to be too narrow for the purpose of this study (Groleau, et al., 2006; Handelman, et al., 2004). Conversely, the conceptual model of asthma disparities based on Institute of Medicine framework was thought to be excessively broad. Applying the model to investigate health care system domain (regulations, insurance reimbursement, health care provider characteristics) as well as the individual domain (socioeconomic, environment, ethnic factors) would require the combined work of a interdisciplinary team (Canino, et al., 2009). However, variables regarding the individual's beliefs about medication and provider/patient communication were of interest (Canino, et al., 2009).

Mishel's Uncertainty in Illness Theory (UIT), a well established nursing theory based on the concept of uncertainty (Mishel, 1988, 1990), was selected to serve as the study's theoretical framework for several reasons. Literature verified that the theory was a valuable framework in the complex care of children and adults with many disease conditions (Y. Lee, Gau, Hsu, & Chang, 2009; McNulty, et al., 2004; Pai et al., 2007; Stewart, Mishel, Lynn, & Terhorst, 2010; White, et al., 2005). The UIT has been successfully applied in prior studies involving ethnic minorities and international subjects (Meleis, 2005; Mishel, 1990; Walker & Avant, 2011). Moreover, the theory will be able to guide the future development and implementation of intervention strategies to alleviate areas of uncertainty (AHRQ, 2007).

Although Mishel's UIT had not been previously applied to Native Hawaiian parents, the theory proved to be applicable and beneficial to the purpose of the study. The UIT guided the

investigation of Native Hawaiian parents' perspective and experiences by identifying multiple facets of asthma care (Lin, Yeh, & Mishel, 2010). The framework was broad and able to incorporate contextual features such as indigenous culture, cultural practices, and health beliefs. The UIT specifically contained constructs and categories that concentrated on the antecedents of uncertainty, modulating factors that increased or decreased uncertainty; and described attributes and implications of uncertainty. Thus, a comprehensive assessment and understanding of parents' uncertainty experience was completed by utilizing the UIT.

The use of focus groups for data collection in this particular study was advantageous for several reasons. Because little was known about the perspective of Native Hawaiian parents, open-ended questions allowed participants to respond in their own words and from their own unique perspectives regarding health, beliefs, values, practices, cultural interpretations, and cultural insights (Bernard & Ryan, 2010). The use of open-ended questions in focus groups facilitated the compilation of new data (Bernard & Ryan, 2010).

The focus groups were conducted in the informal "talk story" format that was an acceptable form of gaining information from Native Hawaiians (Coelho, 2004). Sharing feelings and thoughts in a group setting among other Native Hawaiian parents was compatible with Hawaiian practice that strongly values affiliation with others. Because Native Hawaiians adhere to a collectivist orientation, sharing life experiences and collecting perspectives through focus group was very productive (Fern, 2001).

Listening to the individuals, as well as to the entire group, demonstrated a high regard for affiliative relationships (Consortium, 1985). Additionally, new insights were derived through collective sharing and reflection (Houser, 2008). These varied and complex perspectives

enhanced the understanding of the experiences and added more depth to the data collection in the limited period of time allowed for the study (Macnee & McCabe, 2008).

Focus Group Questions

The focus group questions were developed in consultation with Dr. David Morgan during the International Conference on Qualitative Research: Thinking Qualitatively 2010 at the University of Alberta (personal communication, June 24, 2010). The questions were also evaluated and approved by the dissertation advisor, dissertation committee members, and Dr. Sandra Sinclair, pediatric nurse consultant. Finally, Native Hawaiian parents with children with asthma were consulted regarding the appropriateness of the focus group questions. (See *Appendix H: Focus Group Questions*)

The final version of the eight open-ended questions asked in the focus group discussion was as follows:

1. When did it (illness/asthma) start?
2. What do you do to care for your child with asthma?
3. What things or people have made it easier for you as a parent caring for your child with asthma?
4. What things have made it harder for you as a parent?
5. What is it like for you as a parent taking care of your child?
6. How do you manage caring for your child with asthma?
7. How has your Hawaiian culture influenced you in the care of your child?
8. What matters most to you as a parent about this illness or treatment?

The questions were tested by one non-Hawaiian and four Native Hawaiian mothers with one or two children with asthma. Additionally, two Native Hawaiian researchers with extensive experience with Native Hawaiian focus groups and familiar with the topic of asthma reviewed

the questions. These consultants were asked whether the questions were clear, understandable and logical for the topic of interest. In addition, they were asked whether the questions were offensive, too inquisitive (*nīele*), or insensitive.

There was a consensus that the questions were appropriate and acceptable. The flow or sequence of the questions was satisfactory. However, the initial questions were modified or rephrased because respondents thought the phrasing were unclear or vague. It was also discovered that interview probes were necessary to clarify questions and elicit more information from the respondents (Harrell & Bradley, 2009).

In addition, the dissertation advisor, dissertation committee members, and Dr. Sinclair confirmed that the focus group questions corresponded to the constructs of the UIT. Furthermore, they agreed that the questions were appropriate for an assessment of asthma management and supported the application of directed content analysis using the UIT.

The open-ended questions to the focus group were asked in a “funnel fashion” (Harrell & Bradley, 2009, p.50). In order to facilitate ease and comfort for the participants, the researcher began by first asking one to two broad narrative questions, followed by in-depth questions related to the constructs of the UIT (Burns & Grove, 2011; Morgan, 2010).

The focus group was first asked broad questions related to the parents’ historical experiences (personal story) and perception of the asthma as a disease and treatment. The initial questions promoted *social integration*, which provided equal opportunity for each member to participate in the discussion (Fern, 2001). The two initial questions related to the Stimuli Frame construct of the UIT, which referred to the perception of the disease, signs and symptoms, and treatment.

Then, more in-depth questions provided an understanding of “what makes caring for an asthmatic child easier and what makes it harder.” The questions related to the Structure Provider construct of the UIT. The Structure Provider construct identified factors that modulated the uncertainty experience such as credible authority, social support, and education.

Subsequent questions asked “what is it like for them” as a parent and “how do they manage” caring for an asthmatic child. Their responses added understanding of their appraisal of child caring responsibilities and how they were coping. The answers to these questions furthermore indicated parent’s overall biopsychosocial functioning which addressed the adaptation construct.

One direct question was about culture and its influence on asthma care. The last question was a summative question on the topic (Harrell & Bradley, 2009). The answer to the final question assisted the researcher to prioritize what was most important to the participants.

Sample

A purposeful sampling of Native Hawaiian parents with children with asthma was recruited (Barbour, 2007; Morgan, 2010). In order to obtain the most content and contextually rich sources of experiences, a diverse sampling of participants were recruited (Macnee & McCabe, 2008). There were no restrictions regarding age, socioeconomic status, gender, or number of children with asthma because it was hoped that heterogeneity within the sample population would supply a wide range of perspectives. The inclusion criteria of eligible participants were as follows:

- Native Hawaiian: Either parent claims Native Hawaiian ancestry.
- Biologic Parent: Father or Mother
- Parent must be over 18 years of age
- Child: Age from birth to 18 years of age.

- Gender of Child: Any gender
- Asthma Status: Parent reports child has current asthma.

The inclusion criteria were later modified to admit only parents with more than one year of asthma experience because recruiting parents with less than one year experience proved to be difficult. A change to eliminate the “Early Experience” group was initiated and approved by Dr. Merle Kataoka-Yahiro, dissertation advisor, and UH Committee on Human Studies.

The exclusion criteria included participant characteristics that inhibited their ability to actively participate in focus group discussion. These criteria included presence of mental illness, cognitive impairment, hearing disability, and inability to speak English (Burns and Grove, 2011). The PI explained both the inclusion and exclusion criteria to *key informants*. Then *key informants* were asked to recruit only participants who met the inclusion and exclusion criteria. The Research Informed Consent Form further protected the rights of the participants.

Setting

The focus groups were held in two locations close to the participants’ community of residence between November 2011 and January 2012. Three focus groups were held in Windward O’ahu and one focus group was conducted in Honolulu. The settings were selected based on convenience, accessibility, freedom from interruptions, and sense of safety or neutrality for participants.

Demographic Tool

All participants were asked to complete a demographic survey that sought to obtain information about the age and gender of the child, age and gender of the parent, address, education and occupation of parent, number of children with asthma, duration of child’s illness, social support, health care provider, and health insurance. (See *Appendix I: Demographic*

Survey) The purpose of the demographic information was to identify the affected child; the socioeconomic and educational background of the parent; the availability of social support and health care providers; and access to health care.

Data Collection

This data collection section describes the training of the research team, participant recruitment, and focus group protocol. Data sources included a demographic survey, focus group discussions, and field observation. Data collection began after official approval was obtained from the University of Hawai‘i at Mānoa (UHM), Committee on Human Studies (CHS) for the proposed research, informed consent including consent to audio-record, focus group protocol, demographic survey, and recruitment flyer. The time period for data collection was October, 2011 to January, 2012. (See *Appendices J* and *K* for detailed data collection procedure and protocol)

Training of Research Team

The principal investigator (PI) and one research assistant (RA) comprised the research team. Both members of the research team attended each focus group in order to promote continuity and consistency of data gathering as well as data analysis.

The PI coordinated the entire research project, recruited participants, moderated the focus groups, maintained data, and monitored data analysis. The RA performed a number of tasks such as arranging the physical set-up for focus group sessions, welcoming participants, and assisting participants to complete the demographic survey and informed consent form. During the focus group session, the RA was an observer, note-taker, and in charge of the audio recording. After each focus group, she participated in coding and data analysis.

The PI was the moderator of each focus group. She was trained in interview techniques and how to conduct focus groups through her studies at the University of Alberta and University of Hawai‘i at Mānoa. The PI oriented and provided training to the RA throughout the research project. Both PI and RA completed the web based certification in The Protection of Human Research Participants.

The RA was properly instructed how to collect appropriate data and answer participants' potential questions or concerns. She was oriented to the research process including purpose of study, intention of the questions, recruitment of participants, selection of focus group settings (location, dates, and times for focus groups), confidentiality, field note-taking, collecting data, data analysis, and dissemination of results. The PI instructed the RA on the note-taking format; symbol, notations and abbreviations to be used; and observations to be recorded. Length of training encompassed a total of five hours.

Participant Recruitment

Recruitment of Native Hawaiian participants involved distributing informational flyers, gaining permission from organizational leaders to directly contact prospective participants, and recruiting *key informants* to identify prospective participants and linking them with the researcher. A number of recruitment efforts were directed various groups of Native Hawaiians such as *hula hālau*, canoe clubs, educational programs, and student clubs. *Key informants* and other participants recruited family and friends “by word of mouth.” Informal communication by “word of mouth” was a culturally appropriate method of recruitment, rather than using standard methods such as radio announcements and advertisements (Chang, 2001).

When the PI met with organizational leaders, *key informants*, and potential participants, she explained various aspects of the study including the purpose of the research, focus group

“talk story” format, procedures for recruitment, inclusion/exclusion criteria, incentives, confidentiality, details about focus group date, time and location, and PI contact information. Similar information was included on the informational flyer. The flyer was approved by the UH Committee on Human Subjects before recruitment began. (See *Appendix L: Recruitment Flyer*)

Furthermore, the PI telephoned the prospective participants and/or *key informant* at various intervals prior to each focus group session. The first contact (10-15 minutes) was made two to three weeks before each session to reiterate the research purpose and participant’s involvement. Subsequent telephone contact (5-10 minutes) by the PI at one week and one day prior to the session with each participant and/or *key informant* served to answer any questions and remind the prospective participants of the focus group location, date, and time.

In summary, 17 parents met the inclusion criteria and were considered prospective participants. Seven parents were unable to attend the scheduled session due to various reasons such as illness, birth, conflicting work schedule, inconvenient location, and unwillingness to attend session alone. In addition, two interested adults did not meet the inclusion criteria due to the age of child and not being the biological parent. There were a total of ten participants and four focus group sessions held between November 2011 and January 2012.

Protocol

All interested participants were known as “prospective participants”. Prospective participants were enrolled into the study when they attended a focus group session. Enrollment procedure included signing the informed consent form and completing the demographic survey. The participants were assigned a numerical code according to the sequence of speakers in the focus group. They received a copy of the informed consent form and the incentive prior to the start of the focus group discussion.

Having four groups had the advantage of bringing to light distinct patterns (Barbour, 2007). Homogeneity within the groups promoted a sense of likeness, connection, and comfortable interaction (Morgan, 2010).

Illness duration was calculated by subtracting the date of diagnosis from the date of participation (Carpentier, Mullins, Wagner, Wolfe-Christensen, & Chaney, 2007). All four focus groups consisted of participants with long term asthma experience. The total number of ten (10) participants met the anticipated total number of participants (8-12).

This section describes the focus group procedure that was implemented as well as cultural considerations. Each focus group meeting was carried out in a consistent and orderly manner due to the application of the focus group protocol. (See *Appendix K: Focus Group Protocol*) Each focus group met in one session for 2 hours. The first 15 minutes was devoted to completing the demographic survey and signing the informed consent form. The focus group discussion was 1 1/2 hours in length. Additional time of 15 minutes was allotted for refreshment.

In order to support the parents' cultural values, a number of activities were implemented throughout the study. An example of a culturally appropriate method of introduction included offering one's name, family background, and area of residence (Look, et al., 2008). Although prayer was initially considered, the PI felt insufficiently familiar with the participants to initiate prayer at both the beginning of the focus group interview and at the end to acknowledge and ask spiritual powers for assistance and guidance. The PI later realized that prayer may have been acceptable to the participants after listening to the transcripts. Therefore, prayer was offered at the "*member check*" and second meetings.

It should be noted, however, that introductory and closing activities were not audio-recorded to order to maintain confidentiality and respect to the individual participants.

Throughout the focus group process, warm and affiliative communication (i.e. words of welcome, hand shake, embrace) were generously offered to all participants. These activities demonstrated acceptance and conveyed a sense of affiliation and respect to each individual.

The data collection protocol specified steps that ensured participant attendance and prepared for complete set-up of the physical facility. (See *Appendix J: Data Collection Protocol*) In addition, a list of items was maintained in order to promote efficiency and consistency in the physical set-up and clerical aspects of focus group sessions. (See *Appendix M: Pre-Group Checklist*)

The PI contacted the participants and/or *key informant* one week and the day before the session by telephone or in person. On the day of the focus group session, the RA greeted and asked participants to complete the enrollment process. Participants were given a copy of the informed consent form and the incentives. They were also asked to sign for receipt of the incentives. Participants were encouraged to partake of the refreshments at their leisure.

After the enrollment process was completed by all participants, they were invited to select a chair around a table. All participants arrived within 15 minutes of the scheduled time. As stated previously, a warm welcome and introductions of participants and research members initiated the focus group session. The moderator explained the purposes of the study, digital recorder, and name tents. The role and expectations of the moderator, RA, and participants were also described. “Ground rules” were reviewed in order to protect and respect individual contribution to the discussion. Participants were offered an opportunity to ask questions after the ground rules were reviewed.

The moderator led the focus group discussion by asking questions 1 to 8 in a sequential manner. Ten minutes were allotted for each question. Participants were given an opportunity to offer final remarks after all of the questions had been asked. At the end of the discussion, the moderator summarized the major ideas or perspectives expressed by the group members. A request was made for participants to correct and/or add to the summary in order to have an accurate understanding of the group's main ideas. Finally, the moderator thanked the participants and encouraged them to enjoy the refreshments.

A debriefing session by the research team was held immediately after each focus group session to discuss general impressions, UIT application, most important points, unexpected findings, specific quotes; how the group discussion was similar or different from other groups; and what to change or prepare for the next group session (Krueger & Casey, 2009). The moderator drafted debriefing notes as well as an overall assessment of the group interactions and entered the data file for future analysis.

After the results were transcribed, another group discussion with the same participants at the location of the first group session was arranged by the *key informant* and/or PI to talk about the findings of the focus group. The PI wrote a summary for each focus group. Participants were given a copy of the summary to review. These sessions were termed "*member checks*," and their purpose was to inquire whether the results correctly reflected the participant's perspectives and to check the credibility of the results (Houser, 2008, p. 311).

Three participants attended "*member checks*" meetings with the PI. However, seven participants were unable to attend the meetings due to time constraints or illness. For these participants, two copies of the written summary were mailed to their home address with their permission. The participants were asked to keep one copy and make comments on the second

copy. Then they were asked to return the second copy to the PI in the self addressed stamped envelope for their convenience. Every participant communicated their “*member check*” comments to the PI either in person, writing or telephone. Seven participants concurred with the written summary. Three participants communicated thoughts that were not captured in the summary and/or provided clarification and additions to the summary.

Data Analysis

Data analysis included descriptive analysis of the demographic data and direct content analysis of the focus group sessions. Statistical Product and Service Solutions (SPSS) Version 19 was utilized to produce descriptive statistics of the demographic data including frequencies, percentages, means, and standard deviations.

Data from the focus group sessions were collected from three sources: (a) individual participants’ responses; (b) responses that occurred due to the interaction of the participants as they heard and responded to each other; and (c) consensual and differing group opinions (Macnee & McCabe, 2008). Data analysis of focus group findings consisted of a summary of constructs, categories, subcategories, new themes, and perspectives of the participants in each focus group and among the four groups. Descriptions of experiences and perspectives as well as participants’ quotations provided rich data.

Through directed content analysis, data were investigated in order to understand, digest, synthesize, conceptualize, and re-conceptualize descriptions of feelings, behaviors, experiences, and ideas (Macnee & McCabe, 2008). Subsequently, interpretive coding of the data was conducted to identify constructs, categories, subcategories and new themes (Houser, 2008).

Codes of constructs, categories, and subcategories, and their relationships were predetermined by the UIT (Hsieh & Shannon, 2005). UIT constructs consisted of the Stimuli

Frame, Cognitive Capacities, Structure Providers, Uncertainty, Appraisal, and Adaptation. Categories were branches or off-shoots of constructs. Subcategories became more specific dimensions of categories.

The Stimuli Frame construct separated into categories including Symptom Pattern, Event Familiarity, and Event Congruency. Cognitive Capacities consisted of one construct. The Structure Provider construct had three categories of Credible Authority, Social Support, and Education. The Uncertainty construct had four categories: Unpredictability, Ambiguity, Lack of Information, and Complexity. The Appraisal construct divided into either Inference of Danger or Illusion of Opportunity. The Inference of Danger led to coping categories: Mobilizing Strategies and Affect Control Strategies. The Illusion of Opportunity contained one category: Buffering Strategies. Finally, the construct of Adaptation involved two categories of Goal Directed Adaptation or Adaptation Difficulty.

These codes were tested if they were applicable to the data obtained through focus groups. If the UIT directed codes of constructs, categories and subcategories did not reflect data, then alternative codes were created to identify new themes (Hsieh & Shannon, 2005). Additional codes were generated or combined as new themes emerged.

A professional transcriptionist transcribed the audio recording of group discussion verbatim. The PI validated the transcription by simultaneously listening to the audio recording and reading the transcription line-by-line. Data were collected through hand-written notes and observations by the research team members, as well as via digital recording. During each session, the RA took field notes in order to capture observational data that was absent in the digital recording. Non-verbal activity that was recorded included nods, physical excitement or positioning, eye contact that was made between certain participants, tone of voice, or other clues

that indicated the level of agreement, support or interest (Morgan, 1998). A sketch of the seating arrangements was also drawn.

The audio-digital data was transcribed verbatim by the transcriptionist. This meant converting the audio recording into digital text (Bernard & Ryan, 2010). Later, the recording was audited in tandem with a reading of the typed transcription by the PI. This process served several purposes: proofreading the transcription, gaining a sense of the entire interview, and capturing emerging ideas. Details such as voice tone, inflection, pauses, and observational notations were added to the typed transcription by the PI (Burns & Grove, 2011).

Two research team members and an external reviewer read and analyzed the transcripts independently. Directed content analysis using the predetermined constructs and categories of the UIT guided the interpretation of the data. The research team members also met and communicated by email regularly to discuss their analysis and coding interpretation.

Coding was first performed by the research team members manually by paper and pencil, and then data was entered into NVivo. The paper trail of critical decisions was maintained by note-taking and in NVivo during the line-by-line analysis (Burns & Grove, 2011).

The text analysis process began with the list of the participants' responses following each question (Harrell & Bradley, 2009). A search for data took place for each question associated with the constructs and categories of UIT. Identified construct, category, and subcategory within each question were coded. This was prepared by highlighting the selected text and associating it with a particular UIT construct, category, or subcategory in NVivo. Additionally, new categories and subcategories were identified by highlighting repetitive themes (Bernard & Ryan, 2010).

After the data were coded by UIT construct, category, or subcategory, then patterns were sought among the construct, categories, and subcategories. Patterns facilitated an understanding of certain constructs, categories, or subcategories for particular types of parents or situations (Harrell & Bradley, 2009). Moreover, a pattern of relationships among constructs, categories, and subcategories evolved. Through the process of construct and category identification and comparison of data, key ideas that frequently reflected the meaning of the data were established (Burns & Grove, 2011). An orderly combination of constructs, categories, and subcategories was carefully defined in order to prevent overlapping of groupings.

Eventually, data saturation occurred, and information appeared redundant with no new information being gained. This became clear when newly acquired pieces of information or data were placed into the established coding system of previously identified and defined UIT constructs and categories (Macnee & McCabe, 2008). Furthermore, each UIT construct, category, and subcategory contained applicable coded data. After Focus Group 4 transcripts were reviewed and coded, the research team and dissertation advisor determined that data saturation had been achieved; and data collection ceased. The dissertation advisor, research assistant and the external reviewer concurred that appropriate data had been coded for each UIT construct, category, and subcategory. They also agreed on the new subcategories that emerged.

Additional features of data analysis included a line-by-line reading through which unexpected issues or relationships were discovered. Concentrated topics were identified in each focus group. Participants who contributed to specific topics most frequently were identified; and their engagement thoughtfully considered.

A codebook was created through this process of data coding according to the UIT constructs, categories, and subcategories. The definitions entered into the codebook for each

construct, category, and subcategory adhered to the theory's original definition and usages. Four new subcategories emerged from the focus group content. The new subcategories were originally defined by the research team then confirmed by the dissertation advisor and external reviewer.

After the transcription had been validated to be correctly transcribed by the two research members, the transcription and coded material were made available to the external reviewer and dissertation advisor. The external reviewer also utilized NVivo to complete the content analysis independently.

Assurance of Rigor

Rigor was ensured by maintaining a strict process of data collection and analysis. Aspects of rigor in qualitative research included trustworthiness of the data collected, confirmability (consistency and ability to duplicate decision making regarding data collection and data analysis), and credibility of the findings (Macnee & McCabe, 2008). Reliability of the findings was also assured through an external check of the data and analysis.

Trustworthiness of Data

Trustworthiness referred to the truthfulness of the data collected from the participants. In order to assure that the focus group questions were understood, the questions were tested by consultants who met the participant inclusion criteria. The questions were later revised and written in order to be clearer and understandable. The location of focus group discussion was selected on the basis of participants' comfort level, and to be a place where they were able to freely share their thoughts (Krueger & Casey, 2009).

In order to collect trustworthy data, only participants who were interested in sharing their feelings and perspective were recruited. Trustworthiness of data collection was further

supported by the use of consistent focus group protocols to collect data (Macnee & McCabe, 2008) and systematic analysis procedures (Krueger & Casey, 2009). (See *Appendix K: Focus Group Protocol*)

Confirmability

The use of NVivo enhanced the rigor of data collection, or *confirmability*, regarding the process of data collection and analysis (Macnee & McCabe, 2008). The program facilitated the careful examination of data and the organization of categories (Krueger & Casey, 2009). Additionally, NVivo was used to maintain an *audit trail* of ongoing documentation regarding decisions, collection processes, field notes, theoretical notes, and method notes regarding approaches to categorizing or organizing data (Macnee & McCabe, 2008).

Credibility

Credibility, or confidence in the rigor of the study findings, was tested by the PI. Participants were asked to determine if the key findings listed by the PI at the end of the focus group discussion addressed their shared statements. The PI later contacted each participant and asked for their feedback (“*member check*”) regarding the accuracy, completeness, and interpretation of the group discussions (Macnee & McCabe, 2008, p. 172). A written summary was completed by the PI and given to each participant. “*Member checks*” were carried out in meetings with three participants. Seven participants were unable to meet with the PI due to time constraints or illness. Those who were unable to meet with the PI were given a copy of the written summary. Every participant communicated their “*member check*” comments to the PI either in person, writing or telephone. Seven participants concurred with the written summary. Three participants communicated additional thoughts that were not captured in the summary and/or provided clarification to the summary.

Reliability

The focus group protocol was carried out for each meeting. Participants were interviewed in one focus group session and one “*member check*” session. Participants unable to meet with the PI for “*member check*” communicated their opinions in writing or by telephone. All participants’ comments were added to the written summary and considered as data for analysis. Stability was maintained throughout the study by having the PI serve as moderator for each focus group. In addition, the focus group protocol was carried out in each focus group; and the eight focus group questions were similarly asked.

Internal consistency was maintained by having both team members attend each focus group discussion. Internal consistency and inter-rater *reliability* of the coding system was achieved by having the two researcher team members discuss and determine coding interpretation separately and as a team (Bernard & Ryan, 2010); and by an external reviewer. The team approach and having an external reviewer to complete data analysis minimized the effects of bias regarding the findings and performed a *reliability check* (Fern, 2001).

The *reliability check*, or ensuring *external rigor*, was achieved by enlisting the assistance of Dr. Hatsumi Taniguchi, the external reviewer and outside qualitative researcher, to independently analyze the data (Fern, 2004). She reviewed the text material in each code; and verified that the coding was correct. She linked her comments regarding specific texts through the annotation feature of NVivo.

Data Management

The NVivo version 9 software program managed the data and assisted in the analysis of the findings. The primary reason for selecting the NVivo computer software program was its

ability to manage large amounts of group data (Krueger & Casey, 2009). NVivo is an internationally established computer software program specifically created for qualitative research (NVivo, 2011). NVivo is able to accommodate various qualitative research methodologies including descriptive research, action based research, grounded theory, ethnography, and phenomenology. It is designed to creatively manage and analyze non-numerical, unstructured, and text data. A variety of data format can be inputted, such as audio files, videos, Word documents, spreadsheets, rich text and plain text. Data management activities include coding or classifying information, sorting, and arranging data.

Dr. Guenther Krueger provided advanced instruction and consultation to the PI during the NVivo Software Training on Feb. 23-24, 2012 at the University of Alberta. He is a QSR International official NVivo trainer. Dr. Krueger agreed with the PI's plan to code by UIT constructs; and conduct analysis by examining relationships between constructs, participants' attributes, and focus group questions. His advanced NVivo instruction regarding focus group data clearly enhanced the study's data management and analysis.

Data organization for the electronic NVivo database of each focus group included file names, transcription, field notes, background information about the session, list of participants, and general impressions. A spreadsheet was created to keep track of data status such as focus group dates, transcription status, review of transcription, and coding completion (Harrell & Bradley, 2009).

The file management system incorporated the NVivo node classification scheme of each UIT component, focus group discussion, participants' attributes, and compilation of the participants' answer to each question. This system provided readily available information about

each individual and facilitated easy recall when dealing with a number of focus groups and respondents (Harrell & Bradley, 2009).

The PI entered the transcription into NVivo after each group meeting and before the next focus group was held. Data monitoring was maintained through a storage system that kept each focus group data labeled and separate in one location in the double locked file cabinet in the PI's office.

Protection of Human Rights

Protection of human rights is an essential activity, particularly for indigenous populations (Brant et al., 1999). Application to the Committee on Human Studies at the University of Hawai'i at Mānoa was submitted and later approved on September 26, 2011. The research team was comprised of one RA and PI. Both research team members received IRB training and completed the web based certification in The Protection of Human Research Participants.

Informed consent was obtained from each participant and information about the study was disseminated to the participants through a written copy of the informed consent document and verbally in a face-to-face discussion. (*Appendix N: Informed Consent Form*). Information about the study included the title, purpose, PI, the nature of participants' responsibilities, timeframe, consequence of leaving the study before its completion, foreseeable risks and discomforts, benefits to participating, alternatives available for participation, confidentiality, costs to be incurred by the participant, incentive, right to withdraw or refuse to participate, and contact information if participant had questions.

The PI provided additional information regarding the focus group structure and organization including details such as the setting, note-taking, observation and audio recording activities; responsibilities of the moderator and research assistant; and details regarding the focus

group format. Participants were notified that they would be asked to complete a sixteen-item demographic information form on the day of the focus group (*Appendix I: Demographic Survey*). The digital recordings were kept in a locked cabinet, and confidentiality was maintained. Participants were also advised that after the transcription was completed, the PI would contact them via telephone or in person, in order to set up a time for the group of participants to review the findings of the focus group. Participants were informed that the researcher is a doctoral student at the University of Hawai'i School of Nursing and Dental Hygiene, and the results would be published as part of her dissertation. The doctoral student's contact information and advisor's name were included in the consent form.

Confidentiality was maintained by assigning a code number to each participant so that names were not accessible on transcribed or written notes. The PI entered the demographic data into the SPSS program. A transcriptionist transcribed the focus group discussion. Later, the transcription material was uploaded into the NVivo program by the PI. The electronic SPSS database and NVivo program, as well as notes and digital recordings, were consistently placed in a double-locked cabinet in the PI's secured office. The PI was the only person with access to the double-locked cabinets. After the analysis had been completed, transcriptions, digital recordings, and written/typed notes were destroyed. The electronic material and database will remain secured in the PI's office but will be destroyed according to the IRB protocol at the termination of the study.

It was hoped that the participants of the research study gained some benefit from their involvement. One benefit of participation related to the nature of the interaction among focus group participants as they listened and responded to each other (Macnee & McCabe, 2008). Another potential benefit for the respondents was the appreciation and respect that was

communicated to each participant by members of the research team. Because new knowledge was gained by this research, participants should be satisfied to have been involved in a worthwhile project that will assist the community at large (Chun, 2008a). It was the intention of this study that the participants would feel supported throughout the research process. Ultimately, they would realize that their experience of responsibility (*kuleana*) in caring for their child with asthma was shared by other parents. Parents were offered an incentive or honorarium for their participation in the form of \$50, as well as fresh poi to share with their families (H. McCubbin, et al., 1993).

At the end of each focus group session, participants voluntarily commented on their experience of the meeting. All participants expressed their hope that their participation in the research would help other parents. Many enjoyed the session, appreciated the opportunity to discuss their child's condition, and felt supported throughout the group interaction.

Summary

Chapter 3 described a qualitative approach using directed content analysis for this study of Native Hawaiian parents caring for their child with asthma. Focus groups similar to “talk story” sessions for Native Hawaiians served as the vehicle for data collection. The focus group protocol, data collection process, and focus group questions have been presented. Each research team member had individual and group responsibilities, with the goals of promoting productive group sessions, comprehensive data collection, organized data management, and rigorous analysis. Directed content analysis guided by the UIT initiated coding and analysis of the data. Rigor was assured by attending to trustworthiness, confirmability, credibility, and reliability of the data. New knowledge and understanding of Native Hawaiian parents' perspective of asthma care will enhance nursing practice, as well as advance the redesign of asthma care.

CHAPTER 4

RESEARCH RESULTS

Chapter 4 provides demographic characteristics of research participants and the data results obtained from focus group interviews. The data is organized according to predetermined constructs, categories, and subcategories of the UIT (Hsieh & Shannon, 2005). New subcategories unique to the asthma experience are identified.

As the intent of the research is exploratory, the perspectives and experiences of the participants are both diverse and similar. The participants' points of view are included as direct comments in order to exhibit the application of the UIT. This chapter identifies and describes factors of uncertainty for Native Hawaiian parents caring for their children with asthma.

Sample Characteristics

Ten Native Hawaiian parents with greater than one year experience caring for children with asthma met in four separate focus groups. The demographic characteristics of the parents were varied. There were, however, more females than males. Most of the families lived in Windward O'ahu. Parents' ages ranged from twenties to fifties, with a mean age of 30 years. The majority of participants were married. All parents completed high school. Six (60%) parents had attended college. Of the six participants who attended college, four had earned a college certificate, associate degree, or a bachelor degree. Current work statuses of the parents were as follows: three (30%) unemployed, three (30%) students, three (30%) working, and one retired (10%). All the children had medical insurance and an identified health care provider. Four (40%) received Medicaid insurance and six (60%) had private health insurance.

The focus groups contained one parent from each family, with no couples as participants. One focus group had two members of one family. These two participants were asked to speak about their own child.

There was a wide range of ages but most of the children were male and the eldest child. Eight (80%) children were male and two (20%) were female. Children's age groups included one (10%) toddler, three (30%) preschool, five (50%) elementary, and one (10%) high school.

The child's position in the family varied: six (60%) eldest, one (10%) middle child, two (20%) youngest, and one (10%) only child. The number of years the children had asthma ranged from 1.5 to 16.5 years, a mean age of 6 years. Six (60%) children were the only child in the family with asthma. Four (40%) children had one sibling with asthma.

Uncertainty in Illness Theory

The study findings indicated that Native Hawaiian parents experience uncertainty while caring for their children with asthma. Each participant shared their perspective and contributed vivid accounts of their uncertainty experiences. The findings are presented according to predetermined constructs, categories, and subcategories of the UIT (Hsieh & Shannon, 2005). New subcategories unique to the asthma experience are described in their respective constructs. (See *Appendix O: Organization of Results: Uncertainty in Illness*)

Construct: Stimuli Frame

The primary antecedents of uncertainty are found in the Stimuli Frame that consist of three categories: (a) Symptom Pattern characterized by variable respiratory symptoms of asthma exacerbations and the unpredictable timing of asthma exacerbations; (b) Event Familiarity or the unfamiliarity with asthma symptoms, asthma triggers, and health care system; (c) Event

Congruency refers to incongruent events such as ineffective treatment modalities. Notably, all parents distinguished unidentifiable asthma triggers, unpredictable effects of asthma triggers, and unknown timing of asthma exacerbations as formidable antecedents to uncertainty that could not be altered or understood.

Category: Symptom Pattern

The major antecedents of uncertainty were related to the variable nature of asthma symptom patterns before an asthma attack and during an asthma attack. There was no clear pattern of symptoms shared among participants. Additionally, young children's asthma symptoms were more difficult to recognize and understand than older children.

Initial symptoms known as primordial symptoms were usually vague and could be attributed to normal behavior, minor illness, or indicate the onset of an asthma attack. Primordial symptoms included changes in appetite, decreased activity level, cold symptoms, and fussiness and irritability.

Respiratory symptoms during an asthma attack were more objective but not consistent. Respiratory symptoms included increased respiratory rate, coughing especially at night, wheezing, circumoral or bluish tinge color to lips, color changes to entire face, and chest retractions. Some asthma symptoms were acute and life-threatening. One participant stated, "we noticed he get hard time breathing [had difficulty breathing] and his lips...turned bluish....the first episode...he was about three months and his lips turned blue and then his whole face...."

Parents also had difficulty recognizing asthma symptoms of young children compared to older children because young children were unable to verbalize their discomfort. One participant recalled a ride in the country.

He was screaming in his car seat, and...he never screams like that, so we took him out of

his car seat and, we tried to calm him down and he wouldn't calm down...then I noticed his breath like he wasn't even breathing and he was just like hyperventilating...

In contrast, older children were able to describe their respiratory symptoms and seek appropriate assistance. They were better able to express themselves and communicate their discomfort. Two children ages 4 to 5 were known to appropriately ask for their "mask" (nebulizer treatment). All school age children and older (n=5; 100%) were able to recognize when their "chest starts to get tight" and communicate their discomfort to their teachers or self-medicate themselves.

Category: Event Familiarity

The Event Familiarity category is composed of subcategories: *Asthma Experience*, *Asthma Triggers* (both new subcategories), and *Health Care System*. Participants' lack of experience or familiarity with asthma and asthma management, triggers, and health care system were identified as antecedents to uncertainty.

Subcategory: Asthma Experience. All of the participants have been caring for their asthmatic children for more than one year. Parents with less asthma experience expressed and demonstrated more uncertainty recognizing asthma symptom patterns, identifying asthma triggers, and implementing asthma treatment. On the other hand, parents with more asthma experience correctly recognized symptom patterns, identified asthma triggers, and administered treatment properly.

All parents distinctly recalled the initial asthmatic episodes and their inability to recognize the symptoms or understand what the symptoms meant. One participant explained how she heard and saw the symptoms but failed to understand what the symptoms meant.

... he was sleeping, it was the middle of the night. And I could hear him gasping for air,

and when I looked into the crib his chest was caving in and I could hear him wheezing. I didn't know what it was...

Those without experience (n=3; 30%) lacked knowledge and understanding about the asthma condition. They reported much confusion and uncertainty about asthma symptoms, asthma triggers, and asthma management. The nature of coughing appeared to be a symptom that required special discrimination. One parent with many years of asthma care experience correctly described the characteristics of coughing related to asthma as, "the dry cough versus the wet asthma cough. The asthma cough, that persistent cough that you hear constantly through the night." Two parents with less asthma experience were confused about the coughing, failing to link it to asthma as it did not seem to make breathing difficult for their young children.

One participant with a young child described her confusion about when to administer nebulizer treatment as, "...her doctor said to give it [medication and treatment] to her [daughter] as needed. But I didn't know when she needed it. When does she need it? When she coughs? I don't know."

Seven (70%) participants reported varied past experiences with asthma that contributed to "event familiarity" status. Past experiences included having asthma or similar respiratory conditions and/or having two asthmatic children. Participants with past asthma experience were familiar with medical terms, asthma symptoms, and types of available treatment modalities. They were able to recognize their child's asthma symptoms without much difficulty. One participant, with asthma herself, expressed her perspective as, "I think it is helpful that I have asthma. I am compassionate to his situation...I can literally sit there and know exactly...how he feels. I think...that helps me as a parent be able to help him in his situation."

Subcategory: Asthma Triggers. Unknown asthma triggers and unpredictable action of asthma triggers were recognized as strong antecedents to uncertainty. The participants learned how to recognize asthma triggers by watching their children react to various situations and objects. However, unidentified triggers created a constant state of uncertainty for parents particularly in unfamiliar environments.

Triggers, in general, were discovered by “trial and error,” appearing in many forms for each individual. General triggers included allergens, irritants, exercise, changes in weather, upper respiratory illness, strong emotions, and foods.

The unknown identity of triggers and unpredictable action of asthma triggers contributed to one participant’s uncertainty. She “was really afraid” of a possible asthma attack when she first took her child “up to the mountain to go to see the snow.” She did not know if there were any asthma triggers in the new environment and if an asthma attack would be initiated.

A parent voiced a common reality for asthmatic people, “We all have different triggers.” As a parent she needed to find her son’s triggers. A number of triggers identified included: weather changes, hot and muggy weather, rain, “vog”, Kona winds, changes in seasons, windy days, dusty days, candle burning in an enclosed house, “smells”, perfumes, flowers, foods, peanuts, peanut butter, having a cold, dust, and too much running or physical activity. One participant described the wide range of triggers that make living in Hawai‘i difficult for asthmatics.

And we live in Hawai‘i. There is [are] cockroaches everywhere so you know if my daughter has her asthma...“Oh no! We are not going [there]. There is [are] a lot of cockroaches.” [Laughter] I don’t know. It is everything...especially living in Hawai‘i with the Kona winds and the vog and the weather changes drastically from sunny to rainy

and just the steam that comes off of the pavement after it rains or the flowers or perfume...

Subcategory: Health Care System. The initial hospital experience was difficult for many parents. They were unfamiliar with the treatment modalities and did not understand the rationale for specific diagnostic tests and procedures. In addition, participants did not report receiving any type of support or help from hospital staff, causing a significant degree of uncertainty. However, parents did recognize the value of the hospital staff and the role that medical facilities played in effectively resolving asthma symptoms.

Three parents described their initial experiences in the emergency room and hospital as being difficult because their children were very ill and required intensive medical attention. One parent described diagnostic procedures as “doing all their tests, poking him with needles.” A participant was distressed when she watched a respiratory therapist “actually suction mucus out of his lungs because he was so severely congested and his airways were so constricted.” Another mother described her initial perspective and experiences in the emergency room as being frequent, long and traumatic.

So we ended up staying at --- for like six, seven hours and he had to have like five breathing treatments...he was screaming and I didn't know what was wrong with him because you know, he is so little, he can't tell you what is wrong. So it was very nerve-wrecking...we ended back up at the hospital like four times since, before he turned one and a half, because of his breathing. It was traumatic.

Three participants expressed confidence in emergency room staff to provide superior medical treatment to their child when home therapy was ineffective. One parent reported, “After giving the nebulizer two, three times [at home], I...rush [rushed] him [to the] hospital. Right

away, the medicine that they gave him is instantly [effective], I mean, cures him right away. I guess they have a stronger medication, yeah?”

Category: Event Congruency

In the context of this study, event congruency referred to treatment that effectively alleviated respiratory symptoms and resolved asthma exacerbations. An event was considered “incongruent” when treatment was ineffective. For example, with each treatment, parents expected a lessening of asthma symptoms and an end to the asthma attack (congruent event). When prescribed treatment proved to be ineffective (incongruent event), parents were responsible for deciding the next course of action.

One mother who was experienced in asthma management provided an example of an incongruent event. She had administered a nebulizer treatment to her child for an asthma exacerbation. If asthma symptoms persisted after four hours, she knew to administer another treatment. She explained a situation where the treatment resolved asthma symptoms for only two hours rather than the usual four hours. She reported her next course of action as, “...it’s [nebulizer treatment] supposed to be lasting four hours, we are not even lasting two, we gotta go in [emergency room]!” This mother appropriately recognized that she lacked adequate medication to resolve the asthma symptoms at home. She knew the child’s asthma exacerbation could possibly worsen into severe respiratory distress without immediate treatment.

Another less experienced parent relied on the pediatrician for advice when faced with the uncertainty of an ineffective treatment situation. She explained her action by saying, “I’ll call [name of pediatrician]. ‘He is showing these [symptoms], this [medication and treatment] didn’t work. What are we gonna do?’”

Construct: Cognitive Capacities

The research team considered a number of factors that may have adversely affected the parents' capacity to understand their children's asthma (process information). Factors included young age, developmental stage, work obligations, high school or college attendance, and raising more than one child. One participant felt "overwhelmed" with her numerous responsibilities.

It was just a little overwhelming for me, like just not being able to be there for him all the time. You know being at school and work, I can't think sometimes. I'm like oh my goodness what am I going to do?

Two young participants were unable to recognize their infants' initial serious respiratory symptoms and did not understand the significance of their children's on-going coughing symptoms. Additionally, one participant could not remember the names of the asthma medicine. Their lack of knowledge and understanding may be related to the parents' young age, developmental stage, and number of social responsibilities.

Construct: Structure Provider

The Structure Provider is a construct comprised of people and educational experiences that offer structure and meaning to events described in the Stimuli Frame. The construct includes three categories: Credible Authority, Social Support, and Education.

Category: Credible Authority

Participants identified health professionals as physicians, pediatricians, allergists, and respiratory therapists. Although Native Hawaiian healing practitioners might have been added to this category, none were mentioned. Health professionals were responsible for providing adequate information about the meaning of symptoms, diagnosis, causes, consequences of symptoms, and treatment modalities. Parents experienced serious uncertainty regarding overall

asthma care if instruction and guidance were poorly communicated. Parents reported a wide range of positive and negative experiences with health care professionals.

Health care professionals were well accepted as credible authorities by all participants. Positive characteristics of a “good physician” included being sensitive to the parent’s concerns, available to talk to the parent outside of office hours, willing to give advice, and able to accommodate the child into the clinic schedule as needed. According to participants, the majority (70%) of health care professionals provided detailed instructions and explanations.

Unfortunately, a few (n=3; 30%) health care providers were unable to communicate clearly and contributed to parents’ uncertainty about asthma care. Health care providers who primarily gave directions without specific and relevant explanation were considered to be unhelpful. One parent said that a doctor gave her “a bunch of medications” and told her to “call us if he doesn’t get better.” Another parent reported having to ask the pediatrician questions about the prescribed medications. Without information, the parent related, “I would have just went [gone] home and did it [administered the medication] every four to six hours.”

A participant encountered a respiratory therapist who was unsupportive and did not provide sufficient information about respiratory treatment.

The first time I took --- to the ER and she was giving him his treatment and he was just laying there screaming. Because I was a first-time mom, I was like [asked], “Are you sure that’s okay? Don’t you think you should pick him up? Can you just like not do that?” She was like [said], “No, it’s better if they scream. They are opening their lungs more.” I’m just like, “But it looks like torture.”

Category: Social Support

Social support for the Native Hawaiian parents was described through participants' indigenous worldview, culture, and cultural values. '*Ohana* served as the participants' primary social support. Community resources also included health care providers, school teachers, and school health aides. Social support assisted parents by decreasing their uncertainties about asthma symptom patterns and asthma management by providing information, service-related assistance, and emotional support. Each participant had varying social support systems. Without adequate social support, parents experienced serious uncertainty about asthma care.

In order to understand the social support system of the Native Hawaiian participants, an appreciation of the '*ohana* in the context of indigenous worldview is necessary. Parents identified the '*ohana* as their most vital social support and primary source of emotional support and service-related assistance. They engaged in traditional interpersonal relationships; and valued affiliation and close bonds between peers and social networks. This category presents vivid personal accounts of participants' social support.

The Hawaiian values of *kōkua* (helping), *mālama* (caring), and *kuleana* (being responsible) were carried out with *aloha* (affection, compassion) to the ill *keiki* (child) by the entire '*ohana* (Chun, 2008b). Furthermore, '*ohana* readily applied the identical cultural values of *kōkua* (helping) and *aloha* (affection, compassion) to parents when they appealed for aid.

'*Ohana* members included a wide range of relatives who for the most part lived in close proximity to the participants. According to Native Hawaiian parents, the '*ohana* consisted of a large circle of nuclear as well as extended family members including spouse, mothers, fathers, sisters, grandmothers (*tutu*), grandfathers, aunts, uncles, cousins, mother-in-laws, and father-in-laws. Participants identified special groups of relatives with asthma experience as their strong

social supports: three mothers, two grandmothers, two mother-in-laws, three nurse relatives, and two friends. A participant spoke about her mother-in-law as being a reliable and constant source of emotional and social support over the years.

What has also made it easy for me through the years is...my mother-in-law. She is severely...asthmatic. So she knows, as soon as the weather changes, she is calling us, "How is --- doing?" Because once she gets onto her nebulizer...then she knows that he is probably affected right now. So she is kind of our little warning sign...which is great! It's like...the alarm system.... So she is really great and she has taught me a lot about how to care for him, yeah.

In addition to providing emotional and social support to participants, many *tutu* and *kupuna* assisted parents with asthma care by performing traditional healing practices. One participant described *tutu*'s assistance and her special relationship with her grandson.

My mother-in-law is 75% Hawaiian. When the kids are sick, she just makes it all better...it is everything from clearing out their nose to rubbing their chest,...she'll take just take a warm compress and take them to bed with her and just lay down in bed with the warm compress on their chest...And I don't know if that is really just a Hawaiian thing versus her just being grandma. "*Tutu.*" They call her...as soon as he gets into the house, the first thing he does is hugs and kisses grandma and she always asks about him...but there is definitely something... there. I think they have that bond, that asthmatic bond going on, yeah.

Participants demonstrated traditional respect for *kūpuna* (elders). Participants reported expressing their appreciation to their *tutu* or *kūpuna* for any asthma advice or assistance they offered. In this way, cultural values of *lōkahi* (harmony) and *pono* (doing what is proper and

good) were maintained. One *'ohana* had four generations of asthmatics: grandmother, mother, Participant, and two children. The participant spoke often about her grandmother's help and instruction about asthma "tricks" that included the use of Vicks, massage, and caffeine drinks.

In many other cases (5), relatives offered cultural remedies to assist children with asthma. The parents did not always understand the purpose of the remedies, but they nevertheless expressed appreciation for the relative's concern. The parents did not always share these practices or beliefs. For example, one parent spoke about a relative offering her son *noni* tea with, "Like here, drink *noni*. I'm like, yeah right. I wouldn't even drink *noni*." The parents, however, did not discourage *tutu* involvement because they recognized that their concerns were genuine. Rather, they accepted *tutu* remedies, applying some and storing others away. As one participant explained, "I do it just to...not fight [argue]... I do it to satisfy them for a little bit."

The participants sought the help of social support to recognize asthma symptoms, understand the meaning of asthma symptoms, determine acceptable treatments, and verify when to seek medical care. Without their assistance, parents would have experienced uncertainty about the asthma condition and what to do for their children during asthma attacks.

Two grandmothers were the first to recognize their grandchild's asthma symptoms and instructed the parent to take the child to the doctor. One participant continued to rely on her mother because her instructions were clear and specific. She reported, "I'll call her, 'Mom, what do I do?' ...I'll...count his breathing and...tell her what it is and she'll be like 'Okay, you need to take him to the ER right now.' ...I'd rather call my mom than the pediatrician..."

Participants frequently mentioned service-oriented *kōkua* that included child care, providers watching for asthma symptoms, administering medication and treatment, and taking the children to medical appointments. A mother stated, "Luckily for me I...always had family

like my sister would babysit when I was in school or when I was working my mom and my dad. And now he [dad] is my babysitter so he knows what to do.” One parent explained her expectations of her babysitters as, “...if he stays home with my cousins or...sisters [I say], ‘If you gotta [must] put him on his machine, make sure you write down the time and how much [medicine].’ So I know so I can have peace of mind.”

Health care providers were considered to be strong emotional supports for the majority of the parents. Five participants cited their physician as someone who “made caring for their child easier.” Additionally, four participants communicated positively with their children’s teachers regarding asthma, citing the need for teachers to monitor the condition of the children and to permit the children to self administer their inhalers as needed.

Not all members of parents’ social network were sympathetic. One participant said, “My family didn’t understand it [asthma]. They didn’t know what it [asthma] was. They always just thought...like, ‘Why is he sick again? What are you doing?’” Another mother spoke about her particular challenge: “I have two kids, but it sometimes feels like I have three kids because my boyfriend is more like the big brother than the dad. I am always constantly [asking], ‘Did you give him his medicine?’”

Three parents did not have any relatives with asthma experience to seek knowledge and advice from. One participant explained that her social network included only her husband. In other cases, five fathers/husbands were reportedly uninvolved with asthma management. Finally, one single parent commented on her situation as being “hard to go through” particularly during a period of time when her baby was seriously ill and hospitalized. As a result of such circumstances, a few participants had limited support.

Category: Education

Education provided additional knowledge and structure to the understanding of asthma for three parents. The research team defined the category of education as any program or degree that conferred college credits. Three participants' college education influenced their ability to organize asthma information and appreciate asthma care. One participant shared how her class helped her:

They are taking us to the garden and...trying to teach us the medicinal purposes of plants versus like prescribed medicines. But it's crazy to know like all those plants have certain purposes...what they can do and what they are supposed to be made for compared to like what we buy at the store. So it's nice to know that there is [are] other options...

Another parent with college education demonstrated a greater knowledge base. As she listened to her focus group discussion, she was able to astutely categorize their experiences and summarized their concerns.

Construct: Uncertainty

The construct of Uncertainty is composed of four categories: (a) lack of information, (b) unpredictability, (c) complexity, and (d) ambiguity. Various emotions will be described as attributes associated to these four categories.

Category: Lack of Information

Parents expressed their need to learn about the asthma condition. When information about asthma was unavailable, incomplete, unclear, or complicated, parents experienced uncertainty regarding basic aspects of asthma and asthma care. Although parents reported growing understanding about asthma as their experience increased, it was a continuous challenge as new situations developed.

All participants contributed comments regarding a lack of information including meaning of the asthma diagnosis, clinical manifestations, seriousness of the illness, prognosis, types of medication, action of medication, side effects of medication, asthma triggers, when to go to the physician office versus emergency room, how to administer nebulizer treatment, and reasons why their asthmatic children were more susceptible to illness. Common among all participants was being overwhelmed with many aspects of asthma when their children were first diagnosed.

I think, in the beginning, what made it harder was that I had no idea what asthma really was....I didn't know it was the inflammation.... I didn't understand how he got it or you know I didn't have it. I didn't know if he would ever grow out of it or...if this would be a life thing that I would constantly have to watch. I didn't know, could it get worse? The hardest thing was just not knowing exactly what it was.

A mother with a young child had difficulty administering the nebulizer treatment. She asked her focus group members, "So how long did it take for the screaming to stop?"

Five participants wondered how their children acquired asthma. One participant said, "[Asthma] could be one *haole* [White person] thing. I don't know." Another member agreed, "I think so. Because it [asthma] wasn't so prevalent back then. So I think something like asthma to have a traditional way of healing, I don't think it was necessary then. Because I see more and more [asthmatic] people now."

A few parents were interested in understanding why so many Native Hawaiians have asthma. Frustration was an emotion specifically related to Native Hawaiians and asthma. One parent commented, "It's just frustrating. What is it about Hawaiians that trigger this asthma?"

Category: Unpredictability

The inconsistent effects of triggers and the unpredictability of asthma exacerbations

created a state of uncertainty for the parents. Moreover, unknown prognosis and questionable effects of chronic medication use were persistent concerns for parents.

All parents experienced “not knowing what” caused an episode and “not knowing when” asthma exacerbations would occur. An experienced asthmatic parent with this unpredictability stated, “One of the most difficult things, I think, is not knowing when it [exacerbation] is going to occur and if it occurs suddenly.”

The effects of asthma triggers were also unpredictable. On occasion, asthmatic children did not suffer any ill effects when they were exposed to a potent trigger. One participant reported, “And fortunately with this past fog...he didn’t have an episode, which was great!”

Two parents had a “hard time sleeping” because they worried about their children’s breathing. One parent said, “It’s just like a constant worry in your head. It never does go away.”

All parents perceived asthma exacerbations to be “scary;” and many felt “fear” for their child. “When they get to the stage where they can’t breathe, it is really scary” for all parents. One parent said, “...when my boy turned all blue...I was wondering [whether] he gonna make it or what [survive]...His lips turned blue.”

Six participants were concerned about the long term prognosis of asthma. One participant asked, “Can a child ‘outgrow’ asthma?” Two parents expressed concern about chronic medication use. A participant commented, “My son took all these medicines and to me it did make him better, but I don’t know about the long-term effects, the future, I don’t know what it’s going to do to his...chemistry or his brain, I don’t know.”

Category: Complexity

The complexities of asthma treatment modalities prescribed by physicians created confusion and uncertainty in parents. Furthermore, interaction with the health care system

contributed to the parents' uncertainty experience.

Parents required more help to understand the purpose for each medication. If parents did not understand the purpose of treatment modalities, they carried out the therapies by rote instruction rather than fully understanding the rationale for the treatment plan. In addition, parents were perplexed about the complex health care system that concerned itself with cost rather than patient need.

All parents expressed confusion about complex aspects of asthma care. One participant said, "And so I would take him to the doctor. They didn't quite say asthma, which I got a little confused about. Because you know...they give him all the albuterol and the prednisone." Another parent described her experience of receiving one prescription by the emergency room doctor, then having the pediatrician adjust the medication two more times.

A parent reported not understanding the asthma treatment protocol when her child was newly diagnosed.

...at first I didn't realize...I should give her machine to prevent [asthma symptoms] and my mom would like scold me, "You need to give her machine, you need to make sure she does it every four hours if she needs it." And I didn't realize how important it was until now...it does prevent her from coughing or getting sick.

Several parents were perplexed and frustrated with their health care insurance that did not cover the cost of nebulizer equipment. A participant dedicated an entire \$200 paycheck to purchase the much needed nebulizer. Another participant did not have the funds to make a similar purchase. The young child was without a nebulizer until an unused nebulizer was secured from an aged family friend who had died.

Category: Ambiguity

Ambiguity involved the difficulty parents experienced, when confronted with subtle, indistinct or confusing respiratory symptoms that appear to be similar to asthma symptoms. Parents required the assistance of their health care provider to establish an accurate diagnosis and treatment plan for ambiguous symptoms.

Two parents specifically spoke about allergy and asthma symptoms as being similar and their need to make a distinction between the two in order to provide appropriate therapies. One parent wondered what her child's symptom of "runny nose" meant and what action to take. She said, "Because he constantly has a runny nose and then it'll go away for a week and it'll come back and it'll stay. So it's like I've never seen him without a runny nose."

Seven participants reported having observed ambiguous respiratory symptoms that were later diagnosed as cold symptoms, croup, or pneumonia. One mother recalled, "He was really young and he had this crazy cough and I was convinced it was asthma. And then I started looking things up. Took him in [to hospital], and come to find out it was croup. That was scary!"

Construct: Appraisal: Inference of Danger

During states of uncertainty, two major appraisal pathways resulted: (a) inference of danger, (b) illusion of opportunity. When uncertain events were potentially dangerous, parents mobilized various coping strategies to minimize or eliminate the uncertain event. Significantly, the appraisal or inference of danger was perceived throughout the study.

Category: Coping Mobilizing Strategies

UIT coping strategies included four subcategories: vigilance, information seeking, direct action-Western, and CAM. The differentiation between therapies, Western and CAM, was a new cultural finding of the study.

Subcategory: Vigilance. Participants applied vigilance as their foremost coping strategy against uncertain events. Parents monitored for asthma symptoms and asthma triggers. Being prepared to properly care for their children in the event of an asthma exacerbation was included in this subcategory. Nine of the ten contributed their accounts of vigilance. One parent described her vigilance.

Being really watchful. I always...have to be on the edge with him. Sometimes even the smell of things or eating certain things can trigger a bout [asthmatic episode]...but in the beginning not knowing exactly what would trigger him was a little difficult because they are not like every other kid; like with sports especially, you know, I can't just [say], "Go out and go play." You know, I have to stay there. I have to make sure that he is going to be able to last the whole game or...that he is not going to have an episode in between...

Three parents reported sleeping with young child during illness in order to monitor their breathing pattern. One participant explained, "I don't know when it's [asthma attack] going to happen. So he is always sleeping with me. He is my cuddle bunny. So then...I can hear him wheezing at night if he ...has a hard time."

Monitoring also involved asking older children questions about their experience. One participant described her conversation with her 10-year-old child as, "I am constantly on him. 'How [are] you feeling? How's your chest? Are you okay? Was that an allergy sneeze?' or 'It's just a tickle sneeze?' "

One parent contributed the most number of comments about vigilance. For instance, she maintained a detailed monitoring system that involved a calendar and recording of symptoms, triggers, and effective treatments in a journal. Another concerned parent described herself as, “I’m just your compassionate mother who hasn’t cut her umbilical cord yet.”

“Being prepared” was consistently linked to monitoring. As one parent cautioned, “But just to make sure you’re prepared is the biggest thing. Because I would hate to be somewhere and not have the machine...and be like stuck with my baby who can’t breathe.” Older children were always prepared for an asthma exacerbation by either carrying the inhaler or storing it in their backpack. Parents took additional medication and the nebulizer machine when they went on overnight visits or trips. For off-island trips, one participant went so far as to pack the “converter... so that I can run the car and run the machine off of wherever we are.”

Subcategory: Information Seeking. Parents sought information about asthma, the nature of the disease, symptoms, triggers, purpose of medications, side effects of medication, how to administer the nebulizer, purpose of the nebulizer, and other treatment strategies. Sources of information included health professionals, ‘*ohana*, friends, and the internet. Community agencies were not mentioned as sources of information. All participants reported seeking information except for one participant.

One participant felt understanding the purpose of the medication was the “key” to successful asthma management. She said, “We had to learn a lot about what albuterol was compared to the steroid. You know, what is clearing out the mucus, what is keeping the lungs open, right?”

All participants identified the health care provider as their primary source of information for medical treatments. In the event the health care professional was unavailable or unclear, participants readily sought the advice and instruction of their social supports.

Google and the internet were important sources of information particularly for three participants. One focus group identified the need for a central repository containing up-to-date pertinent asthma information for Native Hawaiians. One recommendation involved the design of an asthma information page similar to the immunization fact sheet parents receive before the administration of a vaccination. The parent suggested, “Something you can read while you are waiting for the physician to come in.” Another participant recommended having a website for Native Hawaiian parents to refer to that is “a local style asthma control...just something that really defines Hawai‘i.” A different participant further suggested creating an “asthma dictionary” that contains “different remedies” including those from other cultures such as Chinese teas.

The research participants offered several suggestions toward the development of a community resource. A participant visualized a meeting house (*hālau*) placed in a strategic location where Native Hawaiian parents are able to engage in “talk story” sessions in a comfortable setting. They also shared their preference for health education. They viewed conventional asthma health education and teaching strategies as not being engaging. They preferred learning by informally sitting with a small group of Native Hawaiian parents and “sharing stories.” A parent suggested having one central place “that you can go to and people share their *mana‘o*, they share their stories, they share what works and what doesn’t work and with families...I think that would help us a lot in Hawai‘i.”

Additionally, parents in two focus groups gave the research team unsolicited feedback of enjoying the focus group format of “talking story.” A parent shared her perspective.

I think it is...good like all of us talking here. You know it makes you feel comfortable knowing I'm not the only one that does that...now you know these little home remedies that work for each other. You share it with each other and you find out what works.

Subcategory: Direct Action-Western. The subcategory of direct action-Western was specified by the research team as administering medication and treatment prescribed by a health care provider. Additionally, the identification of allergens and protection against allergens were included in this subcategory. Administering Western therapy sometimes was difficult for parents to carry out.

Six parents referred to prescribed medical treatment as being “Western” therapy, “more Western like style,” and “very Western medicine.” Nevertheless, parents collectively reported “resorting to the mask and albuterol” for any indication of respiratory distress. They recognized the reliability of the drugs to effectively resolve respiratory distress when compared to CAM remedies. All participants reported administering albuterol either by nebulizer treatment or inhaler. Several parents specifically administered corticosteroids such as prednisone by mouth or via inhalation.

Participants reported complications when administering some medicines and nebulizer treatment, especially to infants and young children. One parent reported difficulty administering prednisone by mouth to her young child because of its “yucky” taste. Most participants were concerned about the side effects of asthma medication, especially those that made the child “super-hyperactive,” “jittery,” “shaky,” and eventually “drained.”

Three parents learned about allergens from physicians and followed their instructions to protect their children from exposure. One child had to stop eating peanuts and peanut butter. Two participants diligently kept their houses clean because dust was a known allergen to their children. Only one participant spoke about the importance of maintaining good hygiene as a “preventive measure” against colds.

Subcategory: Complementary & Alternative Medicine. In answer to Question 2 “What do you do to care for your child?”, many participants practiced other types of treatment outside of the medically prescribed plan. Three types of CAM therapies were identified and categorized by the research team: (a) comfort measures, (b) home remedies, and (c) Hawaiian cultural healing practices. The four most common reasons for CAM use included preference for natural remedies, familiarity with CAM therapies, difficulty to apply the nebulizer mask to infants and young children, and unwanted side effects of Western medications.

Six parents purposefully implemented CAM strategies before administering the “Western” therapy. Although four participants did not use CAM therapies, they did not prohibit the application of CAM to their child by relatives. A participant explained her rationale for using comfort measures and Hawaiian practices before administering medication.

I think being Hawaiian and being a part of our culture you learn different things...out of the Western way, out of the medicine. Because you don't always want your kid on medicine. I don't want my daughter to be reliant on it [asthma medication]...if at all possible I would rather stick to natural resources and other mechanisms before I give her the albuterol and what-not. And I definitely will...do [CAM therapy]...first.

Comfort measures included stopping their child from running, having them sit and relax, asking them to take deep calming breaths, having them sit in a warm bathtub, “mist in tub,”

having them sit in an air conditioned (AC) car, and allowing their child to sleep upright on the mother's chest. One participant reported, "Where [when] he was struggling, I put him in the car, I started up the AC and we would sit there. In my driveway."

Home remedies were described by one experienced asthmatic parent as "backyard style of doing things and... their own non-Western way of doing things and treating." The remedies were "handed down" to the mothers by their "*tutu*" (grandmothers or older female relatives). Home remedies included applying Vicks to chest, back, and/or underarms; placing warm dry compress on chest; "towel over the head;" eucalyptus oil "under their feet, on their chest," offering hot water or warm tea; placing vaporizer in room; and having child drink caffeinated drinks such as soda and coffee.

Vicks was the most agreed upon CAM product by all participants except for one child who did not like the menthol fragrance. According to family elders, "Vicks is known to cure everything." Many participants remembered their mother or grandmother "used to put some Vicks in a pot of boiling water and you have to go over it and keep the towel over your head so that it keeps the steam in." This procedure was described as their "humidifier."

Parents resorted to home remedies when asthma symptoms occurred unexpectedly and they were without medication. A parent explained her use of soda.

So if we are not at home and I don't have the medicine, I will give her a Pepsi.

[Laughter] She'll slowly sip on it and it works for her. It works for us. So that is my quick escape...it'll last till we...come home.

Tutu or older Hawaiian relatives reportedly believed in superstitions, curses, teas, healing with *ti* leaf, applying warm dry compresses, and *lomilomi*. Participants spoke about other traditional healing practices such *pōpolo* berries, boiling *pōpolo* berry leaves for tea, applying *ti*

leaf to the chest; placing cold *ti* leaf to the head for fever; drinking Hawaiian tea and *noni*, and prayer.

Two parents verbalized praying for their child for healing. Two other participants practiced *lomilomi*. A parent explained, "...with *lomilomi* in your family you learn ...how to bring your child back down to a stable level. Because when they are with asthma they are either shooting up with energy or they are so drained of energy..."

A participant recalled the relevance of the ocean to healing for Native Hawaiians. She repeated what she learned from her *kupuna* (elder) as, "'Take him to the beach, let him go swim in the salt water. Dry it all out.'...When you think about it, they give you a saline solution to squirt up your...nose. So what's the difference? Just go to the beach."

The actual application of Native Hawaiian cultural healing practices among participants was limited. Four participants were not exposed to healing traditions for asthma or respiratory symptoms. One parent recalled the former prohibition of Native Hawaiian cultural practices.

I learned from my mom when she was going [to] school. They told her, "Oh, you have to put your Hawaiian culture on the side." My mom...listens to them. She is not [the] activist kind of person so she [said], "Oh, okay." So a lot of things that we ask her she [is] kind of humble, you know. So she used to listen in school....I mean she really grew up the old Hawaiian way. And she grew up Honaunau, no refrigerator, no electric [electricity]... home is [was] nine miles away [from] school. So she really grew up the real old way and she really didn't pass on what you know her mom taught her...

Another participant further explained the course of historical events as, "With the culture, the language, the art was banned. It was taboo. A lot of our *kūpuna* didn't pass it [healing practices] down to their kids so we've kind of adopted the modern way."

Interest in learning about indigenous cultural practices varied. Five participants expressed avid interest in learning more about traditional healing practices. On the other hand, two participants observed their *kūpuna* (elders) apply healing cures on their children but appeared disinterested in learning more about the tradition and practice.

Category: Affect Management Strategies

Coping strategies that attempted to reduce uncertainty and control emotional responses such as anxiety was known as “affect management” in the UIT (Mishel, 1988, p. 230). For example, when a person believed nothing could be done to modify the uncertainty event and anxiety was heightened, affect management strategies were employed. Affect-management included methods of faith and comparing the patient’s condition to others who were more ill.

There were only two references applicable to this strategy. One parent utilized faith and said, “I know I need to have my faith and everything. Like he’s gonna be okay.” Another parent compared her child’s asthma to a more serious medical situation as, “So as far as his illness goes, I am thankful that it is not something much more severe where he has to be hooked up to a machine 24/7.”

Construct: Appraisal: Illusion of Opportunity

When an appraisal or illusion of opportunity is made, the parent is making an evaluation that an uncertain event is essentially harmless or benign. A category for this construct is buffering strategies.

Category: Buffering Strategies

Buffering strategies block the in-flow of information and included avoidance, denial, selective ignoring, and prioritization. Those parents who were not heavily engaged with their

children's asthma care reportedly exercised more buffering coping strategies than the primary caregivers. Some parents also continued to have hopes of a cure and healing from asthma.

When one participant first learned about her son's diagnosis, she minimized the condition as, "When I didn't know too much about it, I was like, 'Oh, okay. Everyone has asthma. Okay, we'll do some treatments, whatever.'" Another participant also expressed her denial as, "I noticed that he was having a hard time breathing, but I didn't really think of anything because I didn't really think it was a possibility for him to have asthma since I didn't have it."

Five fathers reportedly utilized avoidance and disengagement by going to work and/or leaving the child with the mother to administer asthma care. Mothers reported that fathers perceived asthma exacerbations to be "scary;" and many felt "fear" for their child. One participant described her husband as, "...he's afraid. He doesn't like to see him struggle." Another parent related, "My husband...kind of usually goes a little over the top [excited, upset] only because he doesn't know what it's like." One participant said, "Like for me as a parent, at my young time [when I was young], I was always working, working, working...my wife took care [of] most of the...problems with the kids."

In addition, three parents believed that physical activity would help their children "grow out of asthma." A parent shared, "I like to keep --- active in things. So with sports or running or swimming at the beach...I like to keep --- active to help [child] eventually [and] hopefully grow out of it...that would be my daily thing [activity]."

Construct: Adaptation

The research team defined adaptation as long term behaviors involving biopsychosocial functioning. Positive adaptation involved goal directed behaviors. Conversely, negative

adaptation was labeled as “adaptation difficulty” (Mishel, 1988, p. 231). Adaptation difficulty behaviors demonstrated biologic, psychological, and/or social stressors.

Category: Goal Directed Adaptation

Positive adaptation consisted of everyday life activities that incorporated asthma care so that children could reach their developmental milestones (biopsychosocial functioning). Parents were responsible for managing their children’s asthma competently, transferring their knowledge about asthma and asthma care to their children.

Families of older children demonstrated more goal directed adaptation than those with younger children. Adequate financial and social resources may have contributed to this difference. Parents with older children had essentially more time to establish their households, secure jobs or organize finances to support the family, and “rally” social support. These parents had identified asthma triggers and knew how to select the most appropriate treatment for specific asthma symptoms and triggers. Additionally, asthmatic children became “key players” in their own health by developing sufficient self care abilities to correctly recognize asthma symptoms and self-administer medications independently. The older asthmatic child experienced less frequent exacerbations which significantly diminished the overall uncertainty experience for the parent.

Five parents with long term experiences expressed confidence in caring for their child, recognizing asthma triggers, administering treatment (comfort measures, home remedies, Hawaiian cultural healing practices, and/or Western medical treatment), and determining when they needed more assistance from credible authorities. One group of participants, in particular, stated that they “did not have any trouble now”, “nothing is hard”, and “it [caring for an asthmatic child] is like normal.”

All participants with school age and older children had instructed their children on various aspects of self care. They taught their children how to recognize asthma symptoms, communicate their situation to an adult, and self-administer the inhaler or nebulizer.

Additionally, five participants encouraged their children to engage in normal physical activity. Parents encouraged their children to play in sports (biopsychosocial adaptation). One parent said, “When he played soccer...I mean he’s turning blue on the field, and he’s running out like...give him one shot [inhaler] and he goes right back on.”

One parent explained her goal directed attitude.

So he has played baseball, basketball, swimming, most recently he tried volleyball.

We...don’t want to hold him back. He also sings in a choir. He loves to play music at home and whatever he wants to try, if it’s within our limits, we are going to try it. So he wants to go visit Arizona Memorial...we...[will] go....just to try different things.

Participants with sufficient child care, financial, and social resources verbalized more positive adaptation. For example, five parents were “stay-at-home” parents and did not express much adaptation difficulty regarding the care of their children.

Category: Adaptation Difficulty

Biopsychosocial adaptation difficulties were experienced by all parents. Parents reported lack of sleep due to worry and on-going caretaking responsibilities (biological difficulties). Observing their children struggle during respiratory distress, nebulizer treatment, and medication after-effects was distressful to parents (psychological adaptation). Many people in the community did not understand the children’s asthma symptoms and social relationships may have been affected (social difficulties).

Parents with younger children appeared to have more challenges than parents with older children. They struggled to learn about asthma symptoms, triggers, and treatment modalities. Young children experienced frequent asthma attacks and were vulnerable to minor illnesses. They required continuous care by a responsible adult. Social responsibilities and limited financial resources significantly contributed to participants' adaptation difficulties as well.

Ill children with asthma required attentive caretaking for long periods of time (biopsychosocial difficulty). Participants identified themselves as the primary caretakers of the affected children and many fathers reportedly did not participate in asthma care. Although these mothers did not offer any concerns about fathers' lack of involvement or conflict about asthma management, they expressed the lack of sleep to be a serious concern. One parent shared her difficult season as, "Probably every winter ...I'm up every night, every four hours, albuterol, prednisone for the inflammation, everything."

A parent described her perspective and feelings while watching her child in respiratory distress and receiving nebulizer treatments (psychological difficulty).

And I would cry because I feel so bad for him...he doesn't understand but I know he needs it, you know what I mean? And I have to just fight with him to keep it on and try to take it in. And sometimes when he is so bad and we go into [visit] the doctors, he doesn't take just one treatment, it is like two or three treatments...And he is sitting there just drained out because he has been fighting with us the whole time.

Another participant explained the social difficulty many parents encounter when their children play in public places (social difficulty).

People are like, "Oh! Your kid is sick." "No, my kid is not sick. My kid has asthma"...they are not contagious and I feel like I'm constantly educating people. "She

has...a chronic breathing problem. It is asthma. She is coughing because she is wheezing because she can't breathe."

Educating babysitters, teachers, coaches, and others who were responsible for the care of the child with asthma was a major undertaking (social difficulty). One parent explained her interaction with coaches and other people in the community.

I would have to educate his...coaches on his condition...in case he does have an episode that they know...it is serious and that they can't keep pushing him. He needs to sit out...I guess...educating other people about his situation is a little difficult sometimes...

Parents with young children appeared to have difficulty understanding the asthma condition and the purposes of medications. One parent did not understand why her daughter had a chronic cough and she said, "I guess when you are laying down...maybe it's how she is sleeping it's blocking her air or whatever it is I don't know. But yeah at night and in the mornings when she wakes up, her cough is bad." The mother did not comprehend the purpose of a specific medication (Singulair) to decrease inflammation; and prevent allergic reaction and asthma symptoms. She reported being given instructions by the physician to administer Singulair daily. However, the mother stated, "She doesn't really take that daily. If I give her [nebulizer] machine she'll be fine without it."

Young children were often ill with minor conditions that later developed into asthmatic episodes. A participant expressed her concerns and difficulties.

You... get stressed about, "Did I give her her medicine? I can't forget." You know? It's stressful. And when she's sick it's stressful...because I still have to study and do my work and then take care of her when she is sick. So it's stressful...she is sick so often and she can't miss so much school and I can't miss so much school.

Securing reliable and knowledgeable babysitters was difficult for three participants with young children. One child had three *'ohana* babysitters. The parent developed a system to ensure that a nebulizer machine was easily accessible in each babysitter's home. She shared her concerns in the group discussion.

But, it is hard because [grandmother]...never has given him a treatment. So if it actually comes down to it, I don't know if she'll remember what it is, cause [because] she is...old and she is forgetful. But...I'm never that far away so if she does call me then... So it does feel like I can't leave him for very long.

Finances directly and indirectly affected parents' adaptation challenges. One financial difficulty included private insurances not covering the cost of nebulizer equipment. Five participants reported missing work and/or school to care for their ill children. One focus group engaged in a lengthy discussion about work attendance and "upset" employers.

Two participants shared how absenteeism jeopardized their job and college success. One participant related, "I told my job like I'm sorry if you guys choose to let me go because I'm taking care of my sick child, then do so, but I can't leave my sick son home to care for himself." Another participant admitted, "I almost failed because I didn't come to class a couple of times because he was having asthma problems and I didn't feel good enough to leave him...What if something happened to him?"

Overall adaptation difficulty was experienced by three participants who had young children. They felt stressed and overwhelmed. One parent described her overall situation in the following manner:

I don't know. Being a parent is already hard...to have school, work, taking care of the two boys...It's hard to constantly know what's going on with them when somebody else

has them...when he does get it [asthma attack], it's so random...I'm not always there when it happens so it's just stressful.

Mothers were primary caregivers for asthmatic children. Many fathers were reportedly uninvolved with asthma treatments. All parents were committed to caring for their asthmatic children and made many adjustments. One participant shared her perspective as, "I mean it's not that hard once... you're forced to live with the situation...You gotta adapt and you realize like... okay."

Summary

The data was organized and presented following the UIT framework. Each UIT construct, category, and subcategory was individually addressed and supported by significant statements and quotes made by the participants. In addition, four new subcategories (Asthma Experience, Asthma Triggers, Direct action-Western, and CAM) emerged from the study results.

Antecedents of uncertainty were found in the Stimuli Frame construct that consisted of three categories: Symptom Pattern, Event Familiarity, and Event Congruency. The Symptom Pattern category described the major antecedents of uncertainty as being related to variable asthma symptom patterns and unpredictable onset of exacerbations. No clear symptom pattern was identified. Parents had more difficulty recognizing asthma symptom patterns of younger children than older children.

Event Familiarity category consisted of three subcategories: Asthma Experience, Asthma Triggers, and Health Care System. The new subcategory, Asthma Experience, identified parents with limited asthma experience as having more uncertainty than parents with many years of asthma management. Asthma Triggers was also a new subcategory because unknown triggers and unpredictable effects of asthma triggers were strong antecedents to uncertainty for parents.

Lack of professional support and unfamiliarity with treatment modalities, diagnostic tests, and procedures in facilities of the Health Care System subcategory added to the uncertainty experience of parents with children with asthma. With more asthma experience, parents came to recognize the value of professional staff and health care facilities to effectively resolve asthma exacerbations.

Event Congruency category described ineffective treatment modalities (event incongruency) as being antecedents to uncertainty for parents seeking to resolve asthma symptoms. Parents over time became more knowledgeable about the course of action to take when an uncertain event occurred.

Cognitive Capacities construct investigated factors that hindered information processing and eventually affected parents' uncertainty about asthma care. Participants who were tasked with many roles and responsibilities may have impeded or hindered their ability to process information about asthma symptoms and treatment.

The Structure Provider is a construct comprised of people and educational experiences that offered structure and meaning to the asthma condition and management. The construct includes three categories: Credible Authority, Social Support, and formal Education. Credible Authorities, composed of health care professionals, were primarily responsible to provide information, instructions and explanations regarding asthma and asthma care. However, if health care providers' instructions were vague, unspecific and/or complex, parents experienced uncertainty about asthma symptoms and treatment.

An understanding of the indigenous worldview, culture, and cultural values was necessary to gain insight into the nature of Native Hawaiian parents' social support system. Social Support for participants consisted primary of '*ohana*, friends, and community resources.

Social Support assisted parents by decreasing their uncertainties about asthma symptom patterns and asthma management by providing information, service-related assistance, and emotional support. The number of social supports varied; and some were more helpful than others. The Education category investigated the influence of formal education which provided structure and meaning of asthma to parents.

The Uncertainty construct consisted of four categories. The specific areas of concern regarding the four categories were as follows: (a) lack of information about disease etiology, diagnosis, symptom pattern, and treatment; (b) unpredictability of asthma exacerbations, inconsistent effects of triggers, prognosis, and long-term effects of asthma medication; (c) complexity of treatment and health care system; and (d) ambiguity of respiratory symptoms. Emotions of worry and fearfulness were associated with the unpredictability of trigger effects, unknown asthma triggers, unknown onset of asthma exacerbations, and life-threatening nature of the asthma condition.

The Appraisal Construct included an Inference of Danger or Illusion of Opportunity. Coping Mobilizing Strategies included subcategories: vigilance, information seeking, direct action-Western, and CAM. Culture and historical context influenced the formation of the two latter subcategories: direct action-Western, and CAM. Direct action-Western involved the administration of conventional asthma treatment, concerns about side effects of medication, and protecting children from allergen exposure. CAM remedies were taught to parents by their *'ohana* and included comfort measures, home remedies, and traditional healing practices.

In the Illusion of Opportunity Appraisal construct, uncertain events were considered harmless or benign. Buffering strategies that blocked the in-flow of information included avoidance, denial, and minimization. Parents also hoped for an asthma cure. The gender of the

parent may also influence the utilization of buffering strategies.

Finally, the Adaptation construct consisted of biopsychosocial functioning in terms of Goal Directed Adaptation or Adaptation Difficulty. Most parents with older children were able to respond appropriately to asthma symptoms and encouraged children to engage in activities to promote normal child development. Many parents transferred their asthma knowledge to their asthmatic children.

Adaptation difficulties were directly related to the burden of asthma care, including social acceptance of asthma by the community. Parents with young children appeared to have more adaptation difficulty than parents with older children. Limited socioeconomic resources were strongly connected to adaptation difficulty.

CHAPTER 5

DISCUSSION

Chapter 5 discusses the research findings by comparing and contrasting parents' care of their children with asthma in current literature. The presentation is organized by UIT constructs. The study limitations and future implications for research, nursing practice, and policy conclude this chapter discussion.

Comparing Native Hawaiian Parents' Experience to Literature

The study results described the experience and perspective of contemporary Native Hawaiian parents caring for their children with asthma in the context of uncertainty. The research results were analyzed by utilizing the UIT framework. The UIT components consisting of constructs and categories identified antecedents of uncertainty and factors that increased or decreased uncertainty; and described attributes and implications of uncertainty. Thus, a comprehensive assessment and understanding of parents' uncertainty experience was completed. Native Hawaiian parents experienced added dimensions of uncertainty about conventional asthma care related to indigenous worldview, cultural, historical, and assimilation and acculturation influences. Participants were able to successfully care for their affected children because the Hawaiian worldview or "way of life" included supportive cultural values and continuous social support (Chun, 2006b, p. 2).

Construct: Stimuli Frame

Antecedents of uncertainty were clearly identified in the UIT Symptom Pattern, Event Familiarity, and Event Congruency categories within the Stimuli Frame construct. No clear symptom pattern for asthma was identified. Strong antecedents of uncertainty consisted of the following: variable asthma symptom pattern, unpredictable onset of asthma exacerbation,

unknown triggers, unpredictable effects of asthma triggers, unfamiliarity with the health care system, and ineffective treatment modalities. Asthma symptom patterns of younger children were especially difficult to recognize than those of older children.

Parents with more asthma experience were comfortable recognizing asthma symptoms, identifying asthma triggers, determining the next course of action over a failed therapy, and utilizing the health care system to their benefit. Parents with limited asthma experience described more uncertainty regarding the disease condition and its management.

The lack of a defined symptom pattern was identified as the major antecedent to uncertainty in both the study results and in the literature (Cox & Taylor, 2005; Horner, 1997; Trollvik & Severinsson, 2004). The study concurred with the literature that antecedents of asthma specifically related to variable symptom pattern, unpredictability of exacerbations (Barton, Sulaiman, Clarke, & Abramson, 2005; MacDonald, 1996; Maltby, et al., 2003; van Dellen et al., 2008); and unknown and unpredictable effects of asthma triggers (Hockenberry & Wilson, 2007; Trollvik & Severinsson, 2004).

Ineffective treatment was also found to be an antecedent to uncertainty in both the study and in literature (Barton, et al., 2005; Horner, 1997; Koenig, 2007). The study concurred with the literature that described unfamiliarity with the health care system, such as emergency room, hospital ward, and intensive care unit, contributed to parents' uncertainty experience while their children were hospitalized (Koenig, 2007; Schatz, Rachelefsky, & Krishnan, 2009), and that parents have more difficulty recognizing young children's asthmatic symptoms than for older children (Kieckhefer & Ratcliffe, 2000; Koenig, 2007). Additionally, parents with more experience recognized asthma symptoms and triggers; confidently determined the next course of action over a failed therapy; and utilized the health care system to their benefit (Barton, et al.,

2005; Coffey, 2006; Trollvik & Severinsson, 2004). Parents with limited asthma experience described more uncertainty regarding the disease condition and its management (Barton, et al., 2005; Koenig, 2007)

Construct: Cognitive Capacities

Parents in the study had difficulty processing asthma information when they had multiple roles and responsibilities to competently carry out asthma care. Parents also reported difficulty processing information when their children with asthma were extremely ill and hospitalized which led to sleep deprivation for parents. Similar results were also reported in the literature (Koenig, 2007; Laster, et al., 2009; Trollvik & Severinsson, 2004).

Construct: Structure Providers

The Structure Provider construct identified people and educational experiences that shared information about the asthma condition and management. The study identified health care professionals as the foremost source of information, guidance, and support for parents regarding the asthma condition and management. However, a few health care providers unsuccessfully communicated asthma care instructions. During these incidents, parents experienced uncertainty about asthma symptoms and treatment.

Literature supported the importance and impact of provider-parent collaboration in securing successful asthma care (Ring, et al., 2011; Tse & Palakiko, 2006; Tse, et al., 2005). Parents sought asthma information and guidance from health care providers and emergency room physicians and staff (Boychuk, DeMesa, et al., 2006; Koenig, 2007).

Some participants in the study reported difficulty understanding the physician's instructions and explanations which was also reported in the literature (Koenig, 2007; Laster, et al., 2009; Rance & Trent, 2005; Reece, Silka, Langa, Renault-Caragianes, & Peen, 2009;

Trollvik & Severinsson, 2004). Incidences where parents of affected children experienced uncertainty due to the lack of information and poor communication by health care professionals were also found in Clark et al. (2009), George et al. (2001), Rance and Trent (2005) and Trollvik and Severinsson (2004).

Social supports for Native Hawaiian parents must be understood in the context of indigenous worldview, culture, and cultural values. Social supports consisted primarily of *'ohana* (extended family) but also included friends and community resources. Social supports assisted parents by providing advice regarding asthma management, service-related assistance, and emotional support. The amount of social support varied; some were more helpful than others.

The *'ohana* and the nature of its support for Native Hawaiian parents require an understanding of the cultural meaning and context for the participants. *'Ohana* served as the parents' most vital social support and consisted of a wide range of members including nuclear and extended family members. *'Ohana* promoted an affiliative or "we" "group orientation with mutual caring (*mālama*)" that was more concerned about the group than the individual (McCubbin et al., 1993, p. 1066). Positive behaviors of the "*kanaka mākuā*" ("a good person") included humility, politeness, kindness, helpfulness (*kōkuā*), acceptance, hospitality, and love (*aloha*) (L. McCubbin & Marsella, 2009, p. 377). Traditionally, an assigned member would care for the ill person (*mālama*), and the family elder (*kupuna*) or healer (*kahuna*) would offer prayers and prescribe healing remedies (Handy & Pukui, 1950; Kamakau, 1991). Thus, the *'ohana* cared (*mālama*) for their own members and did not resort to healers outside of their *'ohana*.

In the Hawaiian worldview, children were cherished because they were direct "offshoots" or branches of the *'ohana*. The children (*kamali'i*) derive their stability and strength from the

'*ohana* which was comprised of their parents (*mākua*), elders (*kūpuna*), ancestors ('*aumākua*), and greater God (*Ke Akua*) (Handy & Pukui, 1998; Rezentes, 1996).

Parents shared their personal stories of how they *mālama* their children in the context of the asthma condition. '*Ohana* as social support participated in the *mālama* of the children with asthma as well. The parents described how the '*ohana* members worked together to make the children strong and well. For example, the grandmothers, *tutus*, and elders offered assistance by recommending or applying home remedies and traditional healing practices onto the children. '*Ohana* members and friends also provided emotional support, asthma guidance, child care, and other forms of service-related assistance. Participants did not mention churches, social agencies, or government organizations as being sources of support or assistance.

The number and nature of social supports varied for participants in the study and in literature (Koenig, 2007; E. Lee, Parker, DuBose, Gwinn, & Logan, 2006) and social support may be unavailable and unsupportive at times (Koenig, 2007; Neufeld, Harrison, Hughes, & Steward, 2007). Families in the study practiced a group orientation and mutual caring (*mālama*). Group orientation was commonly found among other indigenous groups of people such as Native Americans Indians (H. McCubbin, et al., 1993). In Asian culture, such as Chinese and Vietnamese, the needs of the extended family (group) were also considered to be more important than individual members (Purnell, 2009).

Emotional and service-related support from partners, extended family, and friends were common findings in literature (Barton, et al., 2005; Koenig, 2007). However, the '*ohana* in the study appeared to be a much larger network of involved relatives than what is included in the literature (Barton, et al., 2005; Koenig, 2007; E. Lee, et al., 2006; Trollvik & Severinsson, 2004).

Additionally, in the literature, fathers played a more active role in asthma care than reported by participants in the study (Svavarsdottir & Rayens, 2003, 2005; Trollvik & Severinsson, 2004, 2005). Unfortunately, the small sample size and the limited scope of the study prevented further discussion of the role of Native Hawaiian fathers in the children's asthma management. The roles and responsibilities of asthma care for both genders in the Native Hawaiian family require further investigation.

Findings in the literature reported parents seeking support and guidance primarily from health care providers or emergency room staff when they were uncertain about asthma symptoms and treatment (Barton, et al., 2005; Boychuk, DeMesa, et al., 2006; Calfee, Katz, Yelin, Iribarren, & Eisner, 2006; Koenig, 2007). Participants in this study reported going to the emergency room only when treatment at home was ineffective. Also, participants reported community social supports to include the health care provider, school nurses, and school health aides. Participants in other studies were likely to utilize more community resources. Examples of these community resources included health care providers, school nurses, churches, and social agencies such as American Lung Association sponsored camps for children with asthma (N. Clark, Mitchell, & Rand, 2009; Laster, et al., 2009).

Construct: Uncertainty

Both the study results and literature concurred that uncertainty was caused by the following: lack of information about disease etiology, diagnosis, symptom pattern, and treatment (Kieckhefer & Ratcliffe, 2000; Koenig, 2007; Reece, et al., 2009; van Dellen, et al., 2008); unpredictability of asthma exacerbations, inconsistent effects of triggers, prognosis, and long-term effects of asthma medication (Barton, et al., 2005; Ng et al., 2008; Trollvik & Severinsson, 2004; Warman, et al., 2009); complexity of treatment and health care system (Cox & Taylor,

2005; Kieckhefer & Ratcliffe, 2000; Sidora-Arcoleo, Yoos, Kitzman, McMullen, & Anson, 2008; van Dellen, et al., 2008), and ambiguity of respiratory symptoms (Koenig, 2007; Pachter et al., 2002).

Participants expressed two concerns about the etiology of asthma that were not found in literature: (a) its foreign origin and (b) Native Hawaiians being more susceptible to the condition. Although this topic requires further research, these preliminary findings have added to the body of the existing literature. Literature identified the etiology of asthma to be related to asthma triggers such as allergens, irritants, exercise, changes in weather or temperature, upper respiratory symptoms, animals, strong emotions, and foods (Hockenberry & Wilson, 2009), child's anatomy and physiology (Pachter, et al., 2002); spiritual causes, heredity, prenatal history, inadequate infant care (Handelman, et al., 2004); and improper internal or environmental balance (Ng, et al., 2008).

Construct: Appraisal: Inference of Danger

In the face of uncertainty, both study findings and literature reported the utilization of coping strategies such as vigilance (Buford, 2004; MacDonald, 1996; Reece, et al., 2009) and information seeking (Barton, et al., 2005; Horner, 1997; Trollvik & Severinsson, 2005). In addition, the study results described two types of therapies utilized by Native Hawaiians: Western therapies and CAM remedies. Study findings of ethnic minorities and immigrant populations utilized these two types of therapies with preference for CAM remedies (Canino, et al., 2006; Chang, 2001; George, 2001; Ng, et al., 2008; Palafox, et al., 2001; Reece, et al., 2009; Sidora-Arcoleo, et al., 2008; Sidora - Arcoleo, et al., 2007). Concerns about the side effects and long term effects of asthma medication were mutual concerns for participants of the study as well as parents in the literature (Barton, et al., 2005; George, 2001; Ko, et al., 2006; Laster, et al.,

2009; Mansour, Lanphear, & DeWitt, 2000; Warman, et al., 2009).

The CAM remedies identified in the study (comfort measures, home remedies, and indigenous healing practices) corresponded to the categories of CAM therapy described in literature. Literature categorized CAM therapy as follows: (a) mind-body interventions, (b) biologically-based therapies, (c) manipulative and body-based, and (d) whole alternative medical systems (Freeman, 2009; Larson, 2007; Li & Brown, 2009; Mainardi, Kapoor, & Bielory, 2009; Mark, 2007; Sidora-Arcoleo, et al., 2008; Sidora - Arcoleo, et al., 2007). However, the study findings did not include energy therapies that were described by Sidora-Arcoleo, et al. (2008).

The diminishing application of traditional Hawaiian healing practices was expressed among study participants and other Native Hawaiians (Chang, 2001; Palafox, et al., 2001). The reasons for the decreasing dependence and application of traditional Native Hawaiian healing practices are not entirely known. The study revealed specific viewpoints regarding traditional healing practices. Participants who were more familiar with indigenous worldview stated that they did not accept the notion of curses and superstitions being responsible for their children's asthma. In addition, they did not believe that traditional healing practices such as the application of *ti* leaf to the child's chest would be beneficial. The taste of Hawaiian teas and *noni* were unpleasant to drink for both parents and children.

The diminishing application of traditional Hawaiian healing practices and increasing use of Western products may be due to the expanding assimilation and acculturation of Western culture; increasing time constraints and preference for quick medical therapies; lack of information about traditional healing practices; and insufficient traditional experts and *kūpuna* (elders) to serve as resources (Broad & Allison, 2002; Chang, 2001; Maltby, et al., 2003). Notably, literature reported both the waning application of traditional healing practices among

indigenous people and ethnic minorities (Pachter, et al., 2002; Reece, et al., 2009) as well as the continuous reliance on these types of practices by immigrants and ethnic minorities (Freidin & Timmermans, 2008; Handelman, et al., 2004; Mazur, et al., 2001; Pachter, et al., 2002; Sidora-Arcoleo, et al., 2008; Sidora - Arcoleo, et al., 2007).

Construct: Appraisal: Illusion of Opportunity

In the Illusion of Opportunity Appraisal construct, uncertain events were considered harmless or benign. In order to maintain this illusion, coping strategies known as buffering strategies were exercised to block the in-flow of information. Buffering strategies such as avoidance, denial, and minimization were evident in the study findings and in the literature (Trollvik & Severinsson, 2004; van Dellen, et al., 2008). In addition, parents in both the research and literature engaged in a search for asthma cures (Cuzzolin et al., 2003; Ko, et al., 2006).

Construct: Adaptation

The study findings concurred with literature that parents became more confident with asthma management as the children grew older (Barton, et al., 2005; Buford, 2004; Calfee, et al., 2006; Jerrett & Costello, 1996; MacDonald, 1996; Maltby, et al., 2003; Wu, et al., 2009). Additionally, the study results and literature reported parents' positive adaptation to the disease condition, promotion of normal growth and development, and transference of knowledge and skill to the affected children (Barton, et al., 2005; Buford, 2004; Kim, et al., 2009; Trollvik & Severinsson, 2004).

Parents with young children had more adaptation difficulty than parents with older children (Jerrett & Costello, 1996; MacDonald, 1996; Maltby, et al., 2003). There was a concurrence that adaptation difficulties related to the constant and overwhelming responsibility for asthma management (Barton, et al., 2005; Coffey, 2006; Tse & Palakiko, 2004).

Furthermore, limited socioeconomic resources were strongly connected to adaptation difficulty for parents (Dowd, et al., 2009; Gern, et al., 2009; Gruchalla, et al., 2009). Socioeconomic difficulties included securing competent babysitters, the need to depend on family for child care and daily needs, absenteeism at work, employment jeopardy, financial stress, lack of sleep, and fatigue (Barton, et al., 2005; Koenig, 2007; Laster, et al., 2009; Ng, et al., 2008; Rance & Trent, 2005; Warman, et al., 2009).

There were discrepancies regarding two topics areas: gaining social acceptance of asthma by the public and conflict amongst family members regarding asthma management. Gaining public acceptance was identified only by the study findings. Conflict between spouses and/or family members regarding the children's health status and asthma regimen were not reported in the study. Moreover, parental and family discord led to stressful adaptation (Jerrett & Costello, 1996; Svavarsdottir & Rayens, 2003; Tse & Palakiko, 2004).

Limitations

Limitations of the study are related to directed content analysis, use of focus groups, scope of research, and small sample size. The limitations of directed content analysis are related to researcher's bias and actions to establish the selected theory as the most appropriate model to direct the content analysis. Data may have purposefully been selected and controlled to correspond to a predetermined outcome. In the case of directed content analysis, manipulating the study's results to correspond to the components of the theory may have been involved. In addition, unique data may be unrecognized if the researcher were predisposed to a set of well defined data.

A number of precautionary measures were taken in order to guard against such biases and maintain objectivity throughout the research process. The researcher followed a standard group

protocol for each focus group. Focus group participants were allowed time to gather their thoughts before answering each question. In addition, having a note-taker safeguarded the moderator from moving out of a neutral attitude as well as asking leading questions.

Inter-coder reliability was enhanced with two members of the research team and an external reviewer participating in the data analysis of each focus group. Hsieh and Shannon's (2005) recommendations to maintain a rigorous audit trail and audit process in order to document neutral and unbiased decision-making were implemented. To counterbalance any potential for bias, an experienced qualitative researcher conducted an independent analysis of the data.

Finally, it is understood that the results of four focus groups cannot be generalized to the broader population (Harrell & Bradley, 2009). The experience of uncertainty regarding asthma care may prove to be different for other groups of parents. The sample may consist of participants with unique characteristics that may not be duplicated elsewhere. For example, most of the participants resided in Windward O'ahu. The area of residence or locale may affect the experience of parents. All participants were educated, a majority (60%) earning college credits. Furthermore, all children had medical insurance and an identified on-going health care provider. Literature confirms that children with health insurance are more likely to seek regular health care (Kim, et al., 2009). Therefore, the children may have had adequate asthma control which lessened the parents' uncertainty experience. The research sample may also have been a self selected group of parents interested in sharing their experiences.

Implications for Future Research, Nursing Practice, and Policy

The preliminary findings of the study contribute to nursing knowledge regarding the perspectives and experiences of contemporary Native Hawaiian parents caring for their children with asthma. Future implications for research, nursing practice, and policy conclude the chapter discussion.

Implications for Future Research

Future research is necessary to continue the exploration of Native Hawaiians' experience and perspective about asthma care. The children's current state of asthma control was not ascertained due to the limited nature and scope of the study. In order to substantiate the participants' report of positive adaptation, it is necessary to expand the research to include the health care providers' perspective. Professional information about asthma control and parental compliance will strengthen the participants' reports of asthma care (Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005). Moreover, intervention studies may be designed to meet the gaps in asthma management (Conn, 2008).

The study's interview questions, focus group format, and application of UIT proved to be applicable and advantageous to the study of Native Hawaiian parents caring for children with asthma. Applying the research design and focus group protocol to a larger group of Native Hawaiian parents will add to the body of literature. Concerns about the sample size and participant characteristics will be satisfied through this effort.

The perspective and experience of Native Hawaiian fathers, in particular, needs further investigation because males were not well represented in the study. A better understanding of the father's role, responsibilities (*kuleana*), and coping strategies should be gathered. Additionally, research should be conducted with *kūpuna* to understand their perspective,

experience, role, and responsibilities regarding asthma care. This information will broaden our understanding of the functioning of the *'ohana* in regards to the care of children with asthma; and further dimensions of culture and indigenous healing practices will be gained.

A mixed method approach is suggested for future research. Quantitative data combined with the current qualitative research design will further our understanding about Native Hawaiian children's asthma status in relationship to parental interview data. Two measures of asthma control include the Action Control Test (ACT), a clinically validated scale to determine asthma control status (QualityMetric, 2002) and the Asthma Functional Severity Scale (Rosier et al., 1994) that assesses four components of asthma control (Canino, et al., 2009). Additionally, a better understanding of the participants' cultural attributes should be obtained by using such measures as the Hawaiian Culture Scale (Chang, 2001).

Future research involving CAM therapies compared to Western treatment should be considered given parental preference for natural remedies. Parents may be very interested to participate in research that studies the effect of physical activity on asthma control.

Finally, intervention studies that decrease the uncertainty experience for Native Hawaiian should be considered. Intervention strategies may include designing and implementing culturally acceptable health education for parents and *'ohana*, guiding parents to effectively communicate with health care professionals, teaching health care professionals how to communicate instructions clearly and in a relevant manner, and developing focused nursing support and education for parents during hospitalization and emergency room visits.

Implications for Nursing Practice

Nursing practice directed toward assisting Native Hawaiian parents to care for their children with asthma in the context of uncertainty are multifaceted. First, Native Hawaiian

parents may experience uncertainty during various points of the asthma illness experience and will require asthma education and astute nursing assistance. Secondly, cultural values, health care beliefs, practices, and preferences need to be assessed before intervention strategies are implemented (Twinn, 2006). Thirdly, Native Hawaiian parents should be given the opportunity to participate in the design of asthma intervention programs (Jordan et al., 2009).

Alleviating Uncertainty

In order to achieve asthma control, parents must successfully learn how to manage their children's overall asthma care. Parents will require clear and repetitive information and explanation about the disease condition, etiology, signs and symptoms, asthma triggers (Warman, et al., 2009), and when to seek regular health care and urgent care (Christman, 1990; Jurgens, 2006). Nurses should pay particular attention to the subjects of pathophysiology, clinical manifestations, and purposes of medication and treatment because such subject matters are unfamiliar and complicated for most people (Pelletier-Hibbert & Sohl, 2001). As discovered in the study, many participants did not understand the pathophysiology of the disease. Therefore, they were unable to recognize the clinical manifestation of asthma or understand the purposes of the medication and treatment. The findings of the study confirmed that nurses should periodically assess whether parents have questions and concerns and listen with a cultural awareness.

Nurses should be able to foresee when situations of uncertainty may be experienced and provide anticipatory guidance (Wallace, 2005). Nurses need to prepare parents for known uncertain events by providing information such as the identity and effects of common asthma triggers; difficulty administering nebulizer treatment to infants and young children; what to do if therapy is ineffective; side effects of medication on biopsychosocial functioning such as

jitteriness and hyperactivity; emergency room procedures and personnel; and the preparation of a list of items needed in the event of an asthma exacerbation.

Nurses should be able to recognize when patients and family members are experiencing uncertainty and provide nursing care to alleviate any insecurity encountered (Pelletier-Hibbert & Sohl, 2001). Nurses need to be sensitive to emotions of worry, fearfulness, confusion, and stress; and expressions of difficulty caring for their child (M. Davis, 2009).

The study recognized the *‘ohana* as significant sources of information and service-related help for Native Hawaiian parents. Nurses should develop collaborations with parents and their *‘ohana* to work through areas or topics of uncertainty. If parents and *‘ohana* are amenable, nurses may design an asthma plan with the family involvement for everyone to understand and follow.

During periods of uncertainty, patients and family members may require additional financial, psychological, and social support. Health care team members including medical insurance representative, social worker, psychologist, and/or counselors will be of help. Nurses may consider having a directory of Native Hawaiian practitioners, community outreach workers, and religious support for interested parents.

It is recommended to practicing nurses to consider the UIT when assessing parents' knowledge, perception and experience of asthma care (Doane & Varcoe, 2005). It is a straightforward guide and ensures comprehensive assessment of asthma care. Nurses will be able to quickly intervene after the area of need or weakness is identified.

Health education materials and websites should be developed as recommended by the research participants in order to decrease uncertainty regarding the lack of information. The participants' recommendations were as follows: an asthma information page similar to the

immunization fact sheet parents receive before the administration of a vaccination; a “local-style” asthma website with content that is pertinent to Hawai‘i; and an “asthma dictionary” that contains “different remedies” including those from other cultures.

Cultural Considerations

Hawaiian culture, historical background, and assimilation and acculturation influences affect the participants’ perspective and experience regarding asthma care. Nurses, therefore, need to become familiar with indigenous cultural values, healing practices and beliefs in order to provide effective and acceptable care to Native Hawaiian parents and their children (Consortium, 1985). Nursing action and behavior should integrate Hawaiian values of *kōkua*, *aloha* for the weak or ill individual (Chun, 2008b), being *pono*, and promoting *lōkahi* (Chun, 2006b). In addition, nurses are encouraged to communicate respect for the *‘ohana* and *kūpuna*.

Nurses may be of further assistance to Native Hawaiians if they are able to adapt policies and procedures to accommodate important Hawaiian values as much as possible. For example, policies that separate patients from family during clinic visits or hospitalization should be less prohibitive (Bushnell, 1993); and non-inclusion of family members when discussing health matters ought to be reconsidered (Bushnell, 1993; McDermott, et al., 1980). Advocating for patients, coordinating care, and avoiding unclear and conflicting information will decrease uncertainty events for families (MacDonald, 1996; Santacroce, 2002).

A culturally accepted style of communication should be initiated and continued through the informal “talking story” approach. Native Hawaiian parents may be reassured about the complex nature of health care facilities if nurses introduced parents to unfamiliar health care personnel and gave them the opportunity to develop meaningful relationships (Lee, 2006). Nurses should provide basic and clear information about any aspect of the health care system

that comes into question. A friendly and unhurried demeanor by the nurse will reassure Native Hawaiian patients and parents that their questions will be welcomed at all times.

Nurses should take advantage of opportunities to integrate cultural values and concepts into health care, health promotion, and disease management (Santacroce & Lee, 2006). For example, the majority of the participants in the study preferred CAM use rather than solely relying on Western therapies. They expressed interest in gaining more information about asthma care including natural methods and products. Several participants expressed a desire to learn more about traditional healing practices such as *lā'au lapa'au* (herbal medicines) in order to re-establish their Hawaiian identity (McCubbin & Marsella, 2009).

Nurses need to assess treatment preferences and be ready to recommend a wide assortment of evidenced-based practices (Sidora-Arcoleo, et al., 2008). For example, beneficial CAM therapies include foods rich in Vitamin A (Kumar, et al., 2002), Vitamin C (Harik-Khan, et al., 2004), and fish oil (omega-3 & omega-6 fatty acids) (Gyorik & Brutsche, 2004). Breathing exercises and relaxation also assist children with asthma (Gyorik & Brutsche, 2004). Additionally, precautionary warnings should not be forgotten. Nurses ought to caution parents about giving children with asthma certain herbal compounds (e.g. ephedra) in conjunction with asthma medications (e.g. albuterol) (Lanski, et al., 2003). Notably, most Native Hawaiian herbal remedies have unknown therapeutic results or side effects. (See *Appendix D: Lā'au lapa'au* (Herbal Medicines))

Asthma Intervention Program

Creating a culturally-based intervention program for Native Hawaiian parents caring for asthmatic children is a future goal. The approach should be based on the strengths of the

Hawaiian people and rely on their culture to give meaning to the purpose and activities of the program (Kana'iaupuni, et al., 2005).

The research participants offered several suggestions toward the development of a community resource and intervention program. A participant visualized *hālau* or a meeting house placed in a strategic location where Native Hawaiian parents are able to engage in “talk story” sessions in a comfortable setting. According to participants in the study, they are willing to *kōkua* by suggesting topics to be discussed and serving as peer mentors. The development of an affiliative and respectful relationship between nurses and Native Hawaiian parents will be a major benefit of this collaboration (Swallow & Jacoby, 2001).

Learning for Native Hawaiians is not only concentrated on the mind but it must also nourish the heart, body and spirit (Kana'iaupuni, 2005). Therefore, *hālau* plans should include singing with musical instruments, a kitchen to prepare and serve Hawaiian cuisine, wide and open living rooms, garden for *lā'au lapa'au* (medicinal plants), and a spacious play area for children. Nurses may encourage parents to engage in special group projects that promote the building of relationships and goal-directed adaptation. Enjoyable projects may include cooking healthy meals, engaging in arts and crafts, working in the garden, and mapping family genealogy. In addition, Native Hawaiian health practitioners, those skilled in *ho'oponopono*, and other guests may be invited to participate in group sessions. The *hālau* environment and activities serve to strengthen and support Native Hawaiian parents to competently care for their children with asthma.

Implications for Policy

Implications for policy change address areas of adaptation difficulty identified in the study. Medical insurance policies should cover the entire cost of nebulizer equipment for

pediatric patients (Lurie, et al., 2009). Without proper equipment, patients will become seriously ill and seek emergency care. In addition, employer policy should be modified to allow parents to take time off from work to care for their ill children with chronic disease. This should be the same policy for educational programs. Additional work or other remedies should be considered to compensate for missed work and/or school hours.

Summary

The exploration of contemporary Native Hawaiian parents' perspective and experience of caring for their children with asthma in the context of uncertainty has been preliminarily completed. The study findings were discussed using the UIT constructs to describe the multifaceted features of uncertainty relative to asthma care. The study results confirmed that Native Hawaiian parents experienced uncertainty while caring for their children with asthma. Limitations of the research have been described and precautionary measures have been put into place.

Directed content analysis and the application of UIT to the study of Native Hawaiian parents' experience proved to be advantageous to the research purpose. Rich interview data was gathered from ten Native Hawaiian parents who participated in four separate focus groups. Data were organized into all components of the UIT. Two new antecedents to uncertainty were identified: lack of past asthma experience and asthma triggers. In addition, the study discovered that Native Hawaiian parents differentiate asthma treatment as being either Western or CAM therapies.

Contextual influences including indigenous world view, cultural values, history, and assimilation and acculturation factors affected Native Hawaiian parents' perceptions and experiences with conventional asthma care. Parents lacked familiarity with prescribed Western

treatment, preferred CAM use, and heavily relied on their *'ohana* for guidance and support during uncertainty in asthma care. *'Ohana* involvement proved to be the strongest, most reliable, and continuous social support for this group of Native Hawaiian parents. Their help significantly lessened parental adaptation difficulties.

Native Hawaiian parents described their perceptions and experiences as personal stories and accounts of how they *mālama* (care for, protect) their children. The descriptions have been rich and revealing. Nurses now have preliminary knowledge about Native Hawaiian parents' preferences and challenges caring for their children with asthma in the context of uncertainty. There is a large ethnic disparity in asthma morbidity rates for Native Hawaiian children. Nurses are urged to continue their expanded efforts in the areas of research, nursing practice, and policy in order to support and strengthen Native Hawaiian parents' care of their children with asthma.

Appendix A
Hawai‘i Child Asthma Statistics

Table A1

State Child Asthma Status for Years 2005 to 2009

Year	Number	%	95% CI
2005	32,986	11.1	[8.5, 13.7]
2006	36,964	12.4	[10.6, 14.2]
2007	36,801	12.1	[10.4, 13.8]
2008	36,738	12.7	[10.9, 14.5]
2009	31,726	11.3	[9.4, 13.1]

Note. CI = confidence interval. Adapted from “Asthma – Child Asthma Status by State, County, BRFSS Age Group, DOH Race-Ethnicity, Gender, Island, Community, Education Level, Employment Status (Grouped), Marital Status (Grouped), Household Income, Poverty Level, Married, Military, Health Care Coverage, for the Year(s) - 2005, 2006, 2007, 2008, 2009”, by Department of Health, 2011, *Hawaii Health Data Warehouse*, p. 1.

Table A2

Child Current Asthma Status by Race-Ethnicity for Year 2005

Ethnicity	Number	%	95% CI
Caucasian	9,540	8.6	[5.3, 12.0]
Hawaiian	10,262	16.9	[8.2, 25.6]
Chinese	n/r	n/r	n/r
Filipino	11,313	15.3	[7.0, 23.6]
Japanese	6,188	10.4	[4.9, 15.9]

Note. n/r (Not Reportable) – Represents cell size restriction of unweighted count < 50. CI = confidence interval. Adapted from “Child Asthma Status by State, County, BRFSS Age Group, DOH Race-Ethnicity, Gender, County-Community, DOH Race-Ethnicity, Education Level, Employment Status (Grouped), Household Income, Island, Marital Status (Grouped), Poverty Level, for the Year(s) - 2005, 2006, 2007, 2008”, by Department of Health, 2010, *Hawaii Health Data Warehouse*, p. 6 - 7.

Table A3

Child Current Asthma Status by Race-Ethnicity for Year 2006

Ethnicity	Number	%	95% CI
Caucasian	14,027	12.4	[8.7, 16.1]
Hawaiian	11,287	17.8	[12.6, 23.1]
Chinese	2,703	14.6	[6.4, 22.9]
Filipino	7,303	9.0	[5.1, 12.9]
Japanese	7,334	12.4	[7.4, 17.6]

Note. CI = confidence interval. Adapted from “Child Asthma Status by State, County, BRFSS Age Group, DOH Race-Ethnicity, Gender, County-Community, DOH Race-Ethnicity, Education Level, Employment Status (Grouped), Household Income, Island, Marital Status (Grouped), Poverty Level, for the Year(s) -2005, 2006, 2007, 2008”, by Department of Health, 2010, *Hawaii Health Data Warehouse*, p. 20 – 21.

Table A4.

Child Current Asthma Status by Race-Ethnicity for Year 2007

Ethnicity	Number	%	CI 95%
Caucasian	13,419	11.7	8.2-15.2
Hawaiian	9,520	15.0	10.2-19.7
Chinese	739	4.4	.0-10.2
Filipino	12,222	14.7	9.1-20.3
Japanese	7,611	12.4	8.0-16.8

Note. CI = confidence interval. Adapted from “Child Asthma Status by State, County, BRFSS Age Group, DOH Race-Ethnicity, Gender, County-Community, DOH Race-Ethnicity, Education Level, Employment Status (Grouped), Household Income, Island, Marital Status (Grouped), Poverty Level, for the Year(s) -2005, 2006, 2007, 2008”, by Department of Health, 2010, *Hawaii Health Data Warehouse*, p. 34-35.

Table A5

Child Current Asthma Status by Race-Ethnicity for Year 2008

Ethnicity	Number	%	CI 95%
Caucasian	15,983	13.3	9.9-16.7
Hawaiian	12,591	17.1	11.6-22.6
Chinese	3,306	13.8	5.8-21.9
Filipino	7,683	11.3	6.2-16.4
Japanese	7,903	11.5	6.8-16.1

Note. CI = confidence interval. Adapted from “Child Asthma Status by State, County, BRFSS Age Group, DOH Race-Ethnicity, Gender, County-Community, DOH Race-Ethnicity, Education Level, Employment Status (Grouped), Household Income, Island, Marital Status (Grouped), Poverty Level, for the Year(s) -2005, 2006, 2007, 2008”, by Department of Health, 2010, *Hawaii Health Data Warehouse*, p. 48 - 49.

Appendix B

Native Hawaiian Worldview and Cultural Considerations

There are numerous traditional concepts that must be understood when considering health and illness for the Native Hawaiian (Cook, 2001). Health in the Hawaiian culture is more than a state of being healthy. Health is defined in the concept of “*ola*: life; a way of living; to be alive” (Chun, 2008b, p. 36). Both Native Hawaiian diet and active lifestyle are inseparable from “*ola*” (Chun, 2008b, p. 36). Healing was traditionally based on identifying the cause of the illness and involved the “whole body and mind and everything around you holistically” including family relationships (Chun, 2008b, p. 18). Six fundamental traditional sustaining concepts, including *pono*, *mana*, *lōkahi*, *mālama*, *kōkua* and *kuleana*, are defined below:

- *Pono* refers to what is good, right, proper, fair, and moral (Pukui & Elbert, 1986) as well as “achieving balance or harmony of body, mind, and spirit” (Oneha, 2001, p. 305). “If *pono* exists, health is maintained” (Oneha, 2001, p. 305).
- *Mana* is spiritual power and authority (Pukui & Elbert, 1986). “The flow of energy that keeps relationships *pono* (balanced, right, and proper) is *mana*. When there is ill health, anger, discomfort, or irresponsibility, there is a loss of *pono* and a loss of *mana*” (Oneha, 2001, p 307). The flow of energy, *mana*, can be restored through various resources particularly related to a safe place, specific land areas (*‘āina*), prayers, and/or rituals. Through the renewed flow of energy, living *pono* can be regained (Oneha, 2001).
- *Lōkahi* is unity, agreement, accord, unison, and harmony (Pukui & Elbert, 1986).

- *Mālama* is to take care of, tend, preserve, and protect (Pukui & Elbert, 1986).
- *Kōkua* means to help, aid, and provide assistance (Pukui & Elbert, 1986).
- *Kuleana* refers to concern and responsibility, area of land (Pukui & Elbert, 1986)

Chun (2008) explains sickness as the opposite of “*ola*” and identified the following five forms of illness: “true” sickness such as a cold; physical injury; illness caused by revenge; family problems; condition related to and only known to the family such as genetic, psychological, or psychosomatic illnesses. *Kahuna lapa‘au* (traditional healers) developed a formula of medicinal herbs, used spiritual methods to ward off evil spirits, and initiated physical and spiritual cleansing to promote harmony and healing (Chun, 1986; Krauss, 2001).

Native Hawaiians are traditionally a spiritual people. They offered chants and prayers to gods, family ‘*aumakua* (spiritual protector), or to the Christian God in conjunction with herbal remedies (Kamakau, 1991; Pukui, et al., 1972). *Mana* is lost through illness. But spiritual *mana* may be restored by prayers and chants (Chun, 2008b).

Elders such as Aunty Machado, a *lomilomi* (Hawaiian therapeutic massage) healer, reiterates that healing comes from God and their relationship with the spirits (Harden, 1999). The healers and their particular instrument, such as plants or massaging hands, are only the channel through which supernatural energy flows (Harden, 1999; Kaholokula, et al., 2008). In other words, it is God who heals.

Ho‘oponopono is the ancient Hawaiian method of problem solving and maintaining peaceful relationships. It is accomplished by gathering all family members to frankly discuss matters that are contributing to a sense of discord between individuals and, thus, the family

(Hiura & Engebretson, 1999). Pukui described the importance of *ho'oponopono* as the key to healing as follows:

My people believed that the taking of medicine was of little help without first removing any and all mental obstructions. When a problem arose in the family affecting an individual or the group as a whole, every member of the immediate family turned to the *ho'oponopono*. Every one of us searched our hearts for any hard feelings of one against the other and did some thorough mental house cleaning. We forgave and were forgiven, thrashing out every grudge, peeve or sentiment among us. In this way, we became a very closely bound family unit (Chun, 2009, p. 4).

The *'ohana* (family, kinship) is one of the most important concepts in the Hawaiian culture because it explains traditional Hawaiian interpersonal relationships (Pukui, et al., 1972). When one member was ill in the family, assigned members would care for the ill person (*mālama*), and the family elder (*kupuna*) or healer (*kahuna*) would offer prayers and prescribe healing remedies (Handy & Pukui, 1950; Kamakau, 1991). Thus the *'ohana* cared (*mālama*) for their own members and did not resort to healers outside of their *'ohana* or clan.

In Hawaiian tradition, the taro plant (*kalo*) is known as the metaphor that illustrates the importance of the family (*'ohana*) to provide strength and stability to the individual. The family heritage is equated to the root of the taro plant. Deep family roots are comprised of genealogy, homeland, roles, relationships, values, beliefs, and customs (Rezentes, 1996). The taro metaphor expands to describe the relationship of children as offshoots or branches of the taro plant (*ohā*). The children (*kamali'i*) derive their stability and strength from the *kalo* roots which are comprised of their parents (*mākua*), elders (*kūpuna*), ancestors (*'aumākua*), and greater God (*Ke Akua*) (Handy & Pukui, 1998; Rezentes, 1996).

The Hawaiian family promoted an affiliative or “we” group orientation and mutual caring or help (*kōkua*) that was more concerned about the group than the individual (H. McCubbin, et al., 1993). Children were taught skills that benefited the entire family.

Native Hawaiians experience a “sense of place and health” through the concept of *kuleana* (Oneha, 2001, p. 308). For Native Hawaiians, their area of land or place is known as their *kuleana* which they take care of (*mālama*) in a heartfelt manner of responsibility for themselves and their ‘*ohana*. The place where they live (*kuleana*) is considered their “anchor” that will be given to the next generation as a legacy (Oneha, 2001).

Indigenous people including Native Hawaiians possess ancient wisdom, enduring tradition, and reassuring belief systems (Cook, 2001). Language is believed to have power (*mana*), therefore, speaking words and phrases not only conveyed knowledge but also spiritual energy (Commission, 1983). It should be understood that the transfer of knowledge from elder or teacher to pupil involved transference of *mana*, thus elevating this connection to a realm higher than the conventional teacher-pupil relationship (Pukui, et al., 1972).

Chun (2006) explained Native Hawaiian educational traditions as receiving and giving knowledge between members of the ‘*ohana*; mutual dependency, relationship and belonging within the community (Chun, 2006a). And respect for the teacher is a paramount feature in the relationship between teacher and learner (Harden, 1999).

Traditional Hawaiian teaching methods include observation; listening to verbal instruction; reflection and memorization; performing the task; questioning or verbal feedback. Indigenous people transfer knowledge through the oral tradition interlocked by relationships between concepts (Kana‘iaupuni, 2005).

Appendix C

Historical Context

The modern, Native Hawaiian experience of trauma is rooted in exploitation and betrayal by foreigners (Blaisdell, 1982; Kame'eleihiwa, 1992; Rezendes, 1996; Silva, 2004). This historical trauma may affect their outlook on the healing practices that are promulgated by foreigners (*haole*) (Bushnell, 1993). Historical negativity is expressed by the Hawaiian term *kaumaha* which means heavy, and figuratively implies being sad, wretched, dismal, downcast, and troubled (Pukui & Elbert, 1986). The “*kaumaha* syndrome” is rooted in collective sadness and moral outrage felt by many Hawaiians” (Rezendes, 1996, p. 37).

A trauma-induced negativity stems from the foreign domination that resulted in loss of land ownership (*‘āina*), devastating infectious diseases, eventual overthrow of the Hawaiian monarchy in 1893, and annexation to the United States in 1898 (Commission, 1983; Kame'eleihiwa, 1992; McDermott et al., 1980). Westerners' expanding influence in Hawai'i during the nineteenth century slowly dictated a new way of life that included a ban against Hawaiian religion, prohibitions on speaking or writing the Hawaiian language in schools and businesses, promotion of a cash base economy, and the implementation of Western style education and land ownership (Hoomanawanui, 2004; Kame'eleihiwa, 1992; Silva, 2004).

Kana'iaupuni (2005) of Kamehameha Schools explained that when the missionaries and other foreigners came to Hawai'i, they instituted the Western educational model of a single teacher instructing a number of pupils housed in one physical location. This new system altered the traditional Hawaiian educational arrangement of family members instructing children how to perform practical skills and understand family concepts in the home and natural settings (Chun, 2006a). Royal children, too, were gathered and enrolled in the Chiefs' Children School to be

taught how to read and write English, as well as Western religious and cultural matters (Irwin, 1960; Kamakau, 1992).

The *ali'i* (royalty) embraced the notion of written language brought by the foreign adventurers, traders, and later missionaries, and appointed readers and tutors to learn how to read and write the Hawaiian language because they regarded the written language as having the same *mana* or power as the spoken word (Chun, 2006a; Kanehele, 1999). Eighty books written in Hawaiian were published between 1824-1846 as well as a number of newspapers (Chun, 2006a). By 1839, the entire Bible was written in the Hawaiian language (Chun, 2006a).

The decline of the populace and changes in political dominance led to the overthrow of the Hawaiian monarchy in 1893 and annexation to the United States in 1896 (Kanehele, 1986; Kanehele, 1999). During this period of change, strong initiatives were made by foreigners to “Americanize” Native Hawaiians. The prohibition of the Hawaiian language in the schools in 1896 contributed to the erosion of culture and decline of the high literacy rate among the Native Hawaiian people (Kana'iaupuni, et al., 2005).

The diminishing numbers of pure-blooded Hawaiians continues to be a source of sadness for this indigenous people (L. McCubbin & Marsella, 2009). Historical records document the population to have been at least 300,000 in 1778 when Captain Cook arrived at the Hawaiian archipelago (Blaisdell, 1982). Native Hawaiians were highly susceptible to infectious diseases such as measles, smallpox, influenza, and leprosy as well as venereal diseases (Consortium, 1985). Low birth rates due to venereal disease and poor nutrition compounded the diminishing population problem (Blaisdell, 1982). The population had been drastically reduced to 40,000 by 1898 at the time of the overthrow of the Hawaiian monarchy (Blaisdell, 1982). This means that 85% of the indigenous population had died within 100 years of foreign contact.

Native Hawaiians have poor health today and “continue to die at younger ages than other Hawai‘i residents of other ethnic groups” (D. Johnson, Oyama, LeMarchand, & Wilkens, 2004, p. 120). They have a higher prevalence of hypertension, type 2 diabetes, obesity, and asthma (D. Johnson, et al., 2004; Look, et al., 2008). Poor health behaviors such as smoking, drinking alcohol, and using illicit drugs continue to be of serious concern (D. Johnson, et al., 2004; Kana‘iaupuni, et al., 2005). There are about 5,000 pure-blooded Hawaiians (those of 100% Hawaiian blood quantum) living today (L. McCubbin & Marsella, 2009, p. 375). McCubbins and Marsella (2009) believe that in 2050, there will no longer be pure-blooded Hawaiians.

Many Native Hawaiians experience pain and anger particularly related to the loss of their land (*‘āina*) and former system of livelihood (Silva, 2004). Native Hawaiian families with children today “have the lowest mean income (\$55,865 versus the statewide average of \$66,413) and the highest poverty rates (18.3% versus 11.3% statewide) among the major ethnic groups in the state” (Ledward, 2010, p. 6). Poverty is higher in rural areas of Moloka‘i and eastern areas of the Big Island, where there is also a high concentration of Native Hawaiians (Ledward, 2010). Almost one-third (32.4%) of the Native Hawaiian children on the Leeward coast of O‘ahu live in poverty (Ledward, 2010).

Native Hawaiians are striving to move the United States government to restore the rights of their sovereign nation through the Akaka Bill. However, setbacks repeatedly occur which may be further demoralizing to many Native Hawaiians.

Appendix D

***Lā'au lapa'au* (Herbal Medicines)**

**Botanically Based Interventions for Asthma:
Effectiveness & Safety of Traditional Native Hawaiian Herbal Medicines**

Hawaiian Name Genus & Species Common Name	Preparation	Therapeutic Actions, Safety, Side Effects
1. <i>A'ali'i</i> <i>Dodonaea</i> <i>viscosa</i>	Tips from <i>a'ali'i</i> branches may be dried & smoked. This treatment should not be used too often for asthma because it tends to make some patients mildly intoxicated. Chewing the fresh sticky tips of <i>a'ali'i</i> as a medicine for asthma may produce much the same effect (McBride, 1975, p. 78).	Unknown
2. <i>'ahina-'ahina</i> <i>Artemisia australis</i> O'ahu wormwood	For asthma make a tea of the silvery leaves of the <i>'ahina-'ahina</i> that have been pounded. Drink five times a day (Gutmanis, 1976, p. 49).	Unknown
3. <i>'ilima</i> <i>Sida fallax</i>	The root bark, mixed with the flowers, was used for asthma. (Krauss, 1981, 9-10)	Unknown
4. <i>kī (ti)</i> <i>Cordyline terminalis</i> (L.) Kunth ti	A liquid made by grinding up a mixture of ti flowers & young leaves, & other plants, was used for asthma. (Krauss, 1981, pp. 15-16)	Unknown
5. <i>ko'oko'olau</i> <i>Bidens waianaiensis</i>	(Krauss, 1981, pp. 21-22)	Unknown
6. <i>Kukui</i> <i>Aleurites moluccana</i> Candlenut	The bark was used for asthma. (Krauss, 1981, pp. 25-26)	Unknown
7. <i>mai'a</i> <i>Musa paradisiaca</i> L Banana	Ripe fruit used for asthma. (Krauss, 1981, pp. 31-32)	Unknown
8. <i>Niu</i> <i>Cocos nucifera</i> L coconut	Unknown	Unknown

<p>9. <i>Noni</i> <i>Morinda citrifolia</i> Indian mulberry</p>	<p>Juice, tea</p>	<p>Laboratory studies indicated that Tahitian Noni® juice (TNJ) may have greater antioxidant activity than some commonly used antioxidants. No confirmation regarding treatment of asthma (National Standard, 2009).</p>
<p>10. <i>Pale-piwa</i> <i>Eucalyptus sp.</i> Eucalyptus leaves or oil (80+)</p>	<p>“When you have an attack of asthma (<i>hānō</i>) get either the bark or oil of the eucalyptus. Put in boiling water and inhale the steam.” (Gutmanis, 1976, p. 84)</p>	<p>Further research is needed to confirm anti-inflammatory and mucolytic activity before this agent can be recommended in upper and lower airway diseases.</p> <p>Severe side effects have been reported in children after small doses of eucalyptus have been taken by mouth or applied to the skin. Eucalyptus is not recommended for use by infants and young children, especially near the face and nose (National Standard, 2009a).</p>
<p>11. <i>Pōpolo</i> <i>Solanum nigrum</i> L. Black nightshade</p>	<p>Unknown</p>	<p>Unknown</p>
<p>12. <i>Pua-kala</i> <i>Argemone glauca</i> Prickly poppy</p>	<p>Get the flower of the <i>pua-kala</i>, a white flower. If the flower leans upland, do not get it. If it stands straight up, get it. The Hawaiian <i>pua-kala</i> is not very thorny. When you get it, pound it soft, add the proper amount of water, and pour (strain). Pray. Drink it. The phlegm comes out. From <i>Na-luahine Ka-'opua</i>. (Gutmanis, 1976, p. 49)</p> <p>Use the beach or prickly poppy that stands upright. Pull it out. And mix with <i>mau'u kukae pua'a</i> grass, one or two thumb and forefinger bunches, the end of two <i>hala</i> keys, twenty-five <i>kukui</i> nuts. From Mrs. Kelly of Hilo. (Gutmanis, 1976, p. 49)</p>	<p>No confirmation usefulness for asthma. Contrarily, may worsen symptoms of asthma (National Standard, 2009b)</p>

<p>13. <i>Puapilipili</i> <i>Desmodium sandwicense</i> Spanish or chili clover</p>	<p>Sun dried leaves are used for treatment of asthma. The leaves are crushed in the hands to granulate them & then smoked in a pipe several times a day. (McBride, 1975, p. 78)</p>	<p>Unknown</p>
<p>14. 'u^{ala} <i>Ipomoea batatas</i> (L.) Poir Sweet potato</p>	<p>Unknown</p>	<p>Unknown</p>
<p>15. 'u^{ha-loa} or hi'^{a-loa} <i>Waltheria indica</i> L.</p>	<p>The roots, leaves, buds & flowers were used, with other plants, for chronic cases of asthma. All the plants were pounded together, the juices pressed out, & liquid strained. Then the strained juice was heated. This liquid was taken every morning for 5 days. (Krauss, 1981, pp. 47-48)</p> <p>Remove the bark from an <i>uhaloa</i> root, a <i>popolo</i> root & an <i>olapa</i> root. Pound or grind these together with a piece of young koa bark, about 4 inches long by one. Splint a joint of <i>ko</i> & grind it into the mixture. Mash one small <i>noni</i> fruit & stir it in. When all ingredients are thoroughly mixed, squeeze out the juice & strain it. A tablespoon should be taken each morning for 5 days, followed by a tea made from <i>amaumau</i>. (McBride, 1975, p. 77)</p> <p><i>Amaumau</i> tea is made from the dried pith of the fern, ground to a powder. About a tsp of the powder is put into a pan containing 2 cups of water. This is boiled & stirred well. Let cool. Strain it through a cloth & drink while it is still warm. (McBride, 1975, pp. 77-78)</p>	<p>Unknown</p>

<p>16. Flaxseed Seeds of flax: <i>Linum usitatissimum</i></p>	<p>Purchase whole flaxseed. Boil it, & use 3 tablespoon 3 a times day. After boiling, add one tablespoon of honey & one teaspoon of medicinal glycerin. Put it into a bottle & take it 3 times a day. It is good for colds, coughs, asthma, & flu. From a Mormon elder. (Gutmanis, 1976, p. 84)</p>	<p>Unknown Omega-3 fats can help reduce the inflammation that is a significant factor in conditions such as asthma, osteoarthritis, rheumatoid arthritis, migraine headaches, and osteoporosis.</p>
<p>17. Indian ipecac <i>Tylophora indica</i> <i>Tylophora</i> <i>asthmatica</i></p>	<p>Chew leaves (Spencer & Jacobs, 1999)</p>	<p>Treat respiratory disorder, mucous accumulation. Alcohol extract produced complete to moderate relief of asthma symptoms.</p>
<p>18. Ginger. <i>Zingiber officinale</i></p>	<p>1 gm of peeled rhizome of ginger plus 4 whole black peppers chewed daily, along with neem and turmeric (Cooper & Yamaguchi, 2004)</p>	<p>Respiratory disorders</p>
<p>19. <i>Vasaka</i> Or Malabar nut tree. <i>Adhatoda vasica</i></p>	<p>Smoked in cigarettes for asthma & tuberculosis.</p>	<p>Source of bromhexine & ambroxol, 2 mucoregulating drugs used in Europe.</p>

Appendix E

Asthma Initiatives and Programs in Hawai'i

In Hawai'i a number of initiatives, studies and intervention projects have been conducted to address the asthma needs of the State of Hawai'i. The DOH established the Hawai'i State Asthma Control Program (HSACP) in September 2002, as mandated and funded by the CDC to carry out the national aim of addressing the high rates of morbidity and mortality of asthma. The HSACP focuses on alleviating the burden of asthma in the communities, collecting data and planning policy, providing links to community resources to work collaboratively, and engaging in intervention programs (DOH, 2011b).

Through the HSCAP leadership, the Hawaii Asthma Initiative was organized to promote collaboration among public and private agencies in order to increase the impact of their efforts through a combined focus on asthma activities (DOH, 2011b). One major outcome of the Hawaii Asthma Initiative was the publication of the Hawaii Asthma Plan 2006-2010, which served to improve the surveillance of asthma (via database), increase the understanding of the burden of asthma, identify gaps in services, develop a more effective health care system, and decrease pollution (DOH, 2011). The Hawaii Asthma Plan will be updated in 2011 to develop a strategic plan for the next 5 years (DOH, 2011b).

The Childhood Rural Asthma Project (CRA Project), funded by CDC through the DOH, encourages community health centers (CHC) to hire community health workers to go into the homes of underserved asthmatic patients and families to give in-home asthma education particularly focused on eliminating triggers in the home environment (DOH, 2010b). The three CHC engaged in the CRA Project currently is Waianae Coast Comprehensive Health Center, Ko'olauloa Community Health and Wellness Center, and West Hawaii Community Health

Center. Additional funding will be required by the end of 2011 in order for this project to continue.

Emergency rooms in Hawai'i have also engaged in delivering educational programs in an attempt to decrease asthma-related emergency room visits (Boychuk, DeMesa, et al., 2006). The Hawaii Child Asthma Research to Elevate Standards (CARES) program provided asthma education to patient and family members in four emergency room departments on O'ahu (Boychuk, DeMesa, et al., 2006). Multidisciplinary emergency room staff, including physicians and nurses, gave asthma care instructions to the patient and family members utilizing a number of strategies such as face-to-face discussions, DVDs, a visual model of the chest, and distributing a written asthma action plan (Boychuk, DeMesa, et al., 2006). Follow-up telephone calls were made to families 3 weeks and 3 months after the emergency room visit. Additionally, contact was made with the primary care provider to discuss the intervention conducted. The results of this intervention study were positive, as demonstrated by the increased written asthma action plans possessed by persistent asthma patients and increased use of controller medication (Boychuk, DeMesa, et al., 2006).

The American Lung Association in Hawai'i has branch offices on O'ahu, Maui, and the Island of Hawai'i (also known as the Big Island) and offers services to the entire state. Its services include providing nationally designed and produced educational materials and organizing asthma camps for school age children to learn about self management of asthma. The Open Airway for Schools Program, is an in-school education program led by volunteer asthma educators to 800 children statewide (ALA, 2010, 2011). Most recently, the Office of Hawaiian Affairs (OHA) awarded a grant of \$28,843 to the American Lung Association of Hawai'i for its *Maopopo Oli Hano* (Understanding Asthma) program. This is a three-part asthma education

program specifically for Native Hawaiians/Part Hawaiians on the islands of O‘ahu, Maui and Big Island involving school age children with asthma, school personnel and parents (ALA, 2011).

The Waianae Coast Comprehensive Health Center (WCCHC) piloted a community-based asthma management program to reduce inappropriate medical utilization, such as emergency room visits, and improve the quality of life for children with asthma (Chan, et al., 2002). WCCHC is the largest medical service provider to Native Hawaiians in the State. In 2000, 806 children under the age of 14 were treated for asthma. Seventy-four percent of the children had Medicaid insurance or were uninsured. The integrated community-based asthma management project identified children with asthma to ensure that they received coordinated medical services, and sent community health workers to offer health education, self management skills and instruction for environmental change to families in the home. More effective asthma control was achieved as evidenced by the decrease in emergency and outpatient visits and fewer reported daytime and nighttime symptoms (Chan, et al., 2002).

HANOCARE, an asthma management program of the Queen’s Physician Group, began its work in 1998, to familiarize physicians about the National Heart, Lung, and Blood Institute treatment guidelines and offer continuous updated medical education regarding asthma management (Chan, et al., 2002). It also offered patient education and pulmonary functioning testing of high school seniors statewide.

The Windward O'ahu Asthma Coalition (WOAC) was established in 1999 to improve the health of asthmatic school age children living in communities in this region (Chan, et al., 2002). The WOAC volunteers participated in health fairs and supplied experts to speak about asthma in various forums.

Partners Against Asthma (PAA) was organized in 2001 in order to improve health outcomes of children with asthma through the efforts of four work teams. These efforts included developing educational materials, educational outreach, data collection, evaluation, and training (Chan, et al., 2002). Emphasis was focused on the poor and children of Hawaiian ethnicity.

Alu Like, Inc., through OHA grant funding, offers elderly Native Hawaiians self-help regarding chronic illness management such as asthma in support groups led by elders (*kūpuna*) (Alu Like, 2011). This particular program does not involve parents or the care of children with asthma.

Three main concerns regarding intervention programs and Native Hawaiian parents need to be addressed. First, there is a lack of stable on-going intervention and educational programs throughout the State. Availability of programs fluctuates based on obtainable funding and participation of active leaders and volunteers. Open Airways, an American Lung Association school-based educational program, has received less funding recently and will be decreasing the number of school contacts. CARES, HANOCARE, PAA, and Windward O'ahu Asthma Coalition are no longer providing asthma services according to G. Kishaba, DOH Asthma Specialist (personal communication, March 31, 2011). The Childhood Rural Asthma Project (CRA Project) funding will end in 2011 so additional funding is required for services to continue.

A second concern relates to the design of intervention programs and attention to culture (Brim, et al., 2008). Although programs such as CARES, WCCHC pilot intervention program, and American Lung Association's *Maopopo Oli Hano* utilize culturally appropriate methods, the specific strategies have not been described in literature (ALA, 2011; Boychuk, DeMesa, et al., 2006; Chan, et al., 2002). The WCCHC reported that they modified the NAEPPA guidelines to be culturally sensitive but the modifications are unspecified in literature (Beckham, Kaahaaina, Voloch, & Washburn, 2004; Burns & Grove, 2011).

The third concern is the insufficient available literature regarding Native Hawaiian parents' perspective of asthma care. The most notable and comprehensive report regarding Native Hawaiian parents' perception of barriers and facilitators to asthma care was completed in 2004. The Family Perspectives of Asthma Project serves as an exemplar for community participatory research involving Native Hawaiian families and community members (Tse & Palakiko, 2006). The Native Hawaiian Health Care System: *Ke Ola Mamo*-Island of O'ahu and *Hui Mālama Ola Nā 'Oiwī*-Island of Hawai'i, and the Department of Pediatrics, University of Hawai'i conducted an in-depth study to understand the barriers to asthma care for Native Hawaiians. Research participants were Native Hawaiian children with asthma, their parents and siblings; community representatives, and traditional and Western health care providers. They completed surveys and/or participated in interview sessions.

The results of the study included the following parental themes regarding asthma care: high reliance on nebulizer and inhaler; reliance on physician's approval; hyper-vigilant, expects young children to comply with treatment; expect older child to tell parent if there are problems; asthma perceived as unifying factor for some families and for others asthma considered divisive; not aware of the seriousness of the disease; unaware when the asthmatic child was having

difficulty with illness (Tse & Palakiko, 2004). The findings of the research project have reportedly been distributed to community organizations in order to facilitate the design of effective, culturally-based, and family-centered asthma care programs.

Appendix F

Uncertainty in Illness Theory

Uncertainty is defined by Mishel (1997) as “the person’s inability to determine the meaning of illness-related events” (p.4). It is a cognitive state that occurs when a person is unable to “structure or categorize an event due to a lack of sufficient cues” (Mishel, 1997, p. 4). The person is unable to assign value to objects or events and unable to predict the outcome (Mishel, 1997). The concept of interest is uncertainty. In the illness experience, uncertainty has four forms: (a) ambiguity concerning the state of the illness, (b) complexity regarding treatment and system of care, (c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability of the course of the disease & prognosis. This study is concerned about the uncertainty experience Native Hawaiian parents may have regarding asthma care. What aspects of asthma care are unclear, hazy, imprecise or confusing?

Mishel is the foremost researcher of the concept of uncertainty and developed a middle-range nursing theory of uncertainty, Uncertainty in Illness Theory (UIT), that “explains how persons construct meaning for illness events” (Mishel, 1988, p. 225). There are four stages in the model: (a) antecedents generating uncertainty; (b) appraisal of uncertainty as a danger (inference) or opportunity (illusion); (c) coping efforts to reduce uncertainty or to maintain uncertainty depending on the perception of the uncertainty event; and (d) state of adaptation. A schematic diagram of the Perceived UIT is found in Figure 1.

The Stimuli Frame consists of the disease symptoms and medical treatment from the patients’ perspective and operates as the foremost antecedent to uncertainty. Cognitive Capacities is explained as the patients’ ability to process information and is affected by their

general cognitive abilities as well as external and internal processes associated with their illnesses or treatment (Mishel, 1988, 1990; Mishel & Braden 1988).

Structure Providers consist of credible authority, social support, and patient education (Mishel, 1988, 1990). Credible authority is essential to ascribe meaning to the symptoms, forecast prognosis, and recommend treatment. Social support supplies the patient with feedback and interpretation of events. Often social support shares and affirms the patient's beliefs concerning the illness and also provides essential services such as transportation and chores. Social support thus lends predictability and consistency to a patient's life circumstance. A patient's educational level and health educational program have been found to be significant factors in the experience of uncertainty. Structure Providers may significantly modulate the uncertainty experience for the patient.

Once an illness event is encountered and uncertainty is experienced, the person decides (appraisal) whether the event is one of danger (inference) or opportunity (illusion). Then, coping efforts to reduce uncertainty or to maintain uncertainty, depending on the perception of the uncertainty event, are undertaken. Finally, a state of adaptation/maladaptation is achieved (Mishel 1988, 1990).

Appendix G

Measurements of Uncertainty

The Mishel Uncertainty in Illness Scale (MUIS) was the only instrument discovered in the literature review that measures uncertainty perceived during illness (Mishel, 1997). The original scale was developed in 1980 to quantify the experience of uncertainty in hospitalized adult patients, with specific reference to their relationships with hospital staff and medical treatment (Mishel, 1981). The (MUIS) was later revised and updated in 1997 as the Mishel Uncertainty in Illness Scale for Adults (MUIS-A) (Mishel, 1997). The instrument is a 5 point Likert-format scale which measures a person's experience from "strongly disagree" to "strongly agree" (Mishel, 1997). The MUIS-A contains 32 items divided into four factor categories: ambiguity, complexity, inconsistency, and unpredictability (Mishel, 1997).

Subsequently, the Uncertainty in Illness Scale (MUIS-A) has been revised into several versions to meet the needs of different patient populations. The MUIS-C is a community form that was designed to be used for the chronically ill individual or family member at home (Mishel, 1997). A separate scale measuring the parents' uncertainty experience concerning their ill children is entitled Parents' Perception of Uncertainty in Illness (PPUS) (Mishel, 1997). The PPUS contains 31 items categorized into four factors: ambiguity, lack of clarity, lack of information, and unpredictability (Mishel, 1997). The PPUS was later revised (PPUS-FM) to evaluate the degree of uncertainty that any family member, such as a spouse or relative, has for an ill family member (Mishel, 1997).

According to Mishel (1997), normative data have been established for all four versions of the Uncertainty in Illness Scales: MUIS-A, MUIS-C, PPUS, and PPUS-FM. The MUIS variants have been translated into a number of languages such as Swedish, German, Korean, Hebrew,

Mandarin, Cantonese, Arabic, Spanish, Greek and Thai (Mishel, 1997). Research is now being conducted using these translated scales.

The Uncertainty in Illness Scales Manual lists 116 contributing researchers who have used the various MUIS scales for a number of conditions such as abdominal aneurysms, asthma, back pain, breast cancer, prostate cancer, lung cancer, HIV disease, myocardial infarction, cystic fibrosis, irritable bowel syndrome, infectious diseases in acutely ill children, and spina bifida, (Mishel, 1997). One instance of MUIS use is related to a study of treatment modalities for adolescents with scoliosis. The MUIS was selected in this quantitative correlation design to examine the relationship of uncertainty, social support, and psychological distress among patients with polio (Neville, 2003). Separate instruments were used to measure social support and psychological distress. There was a “positive correlation between levels of uncertainty and psychological distress” (Neville, 2003, p. 212).

Appendix H

Focus Group Questions

Question	Probe Questions	Cultural Perspective, Language, Value	Focus Group Process	Uncertainty in Illness Theory Constructs
1. When did it (illness/asthma) start?	a. How did you know that your child had asthma?	<i>Mo'olelo</i> (History)	Broad Question	Stimuli Frame: History of illness
2. What do you do to care for your child with asthma?	a. What do you do to help your child every day and during illness?	<i>Mālama</i> (care for) <i>Kuleana</i> (Responsibility)	In-depth Question	Stimuli Frame: Treatment, home management, recognition of signs and symptoms
3. What things have made it easier for you as a parent caring for your child with asthma?		<i>Kōkua</i> (Help, assistance)	In-depth Question	Structure Provider: Credible Authority, Social Support, Education
4. What things have made it harder for you as a parent?	a. What kind of trouble (<i>pilikia</i>) do you have taking care of your child with asthma?	<i>Pilikia</i> (Trouble, difficulty)	In-depth Question	Structure Provider: Credible Authority, Social Support, Education
5. What is it like for you as a parent taking care of your child?	a. What is it like to be <i>makua</i> for your <i>keiki</i> ?	<i>Makua</i> (parent) <i>Mālama keiki</i> (Caring for your child)	In-depth Question	Appraisal of Uncertainty Coping Adaptation
6. How do you manage caring for your child with asthma?		<i>Makua</i> (parent) <i>Kuleana</i> (responsibility)	In-depth Question	Coping Adaptation

<p>7. How has your Hawaiian culture influenced you in the care of your child?</p>	<p>a. What healing practices have you learned from your elders (<i>kūpuna</i>) that you use for your child with asthma?</p>	<p>Teachings of <i>kūpuna</i></p> <p>CAM use</p>	<p>In-depth Question</p>	<p>Influence of culture.</p> <p>Contextual stimuli</p> <p>Credible authority</p>
<p>8. What matters most to you as a parent about this illness or treatment?</p>	<p>a. Please share your <i>mana‘o</i> (thought/opinion) with us about caring for your child with asthma.</p>	<p><i>Mana‘o</i></p> <p>(Opinion, thoughts, wisdom)</p>	<p>Wrap up question.</p>	<p>Priority concern – What is most important?</p> <p>Stimuli Frame</p> <p>Structural Provider</p> <p>Appraisal of Uncertainty</p> <p>Coping</p> <p>Adaptation</p>

*Appendix I***Demographic Survey****'Ohana (Family Information)**

Please help us by getting to know you by answering the following questions:

1. Number of years experience caring for your child with asthma? Circle answer.

Less than 1 year

More than 1 year

Participant's First Name: _____

Child's First Name (First child with asthma in your family) _____

What position in the family is this child with asthma? (Example: oldest child, middle child, youngest child) _____

2. How long has your child had asthma? _____ years

3. Age of child with asthma _____

4. Gender of child with asthma: Circle Male Female

5. Age of parent _____

6. Gender of parent: Circle Male Female

Appendix J

Data Collection Protocol

**UNIVERSITY OF HAWAII at MĀNOA
School of Nursing and Dental Hygiene
Department of Nursing
2528 McCarthy Mall, Webster Hall
Honolulu, HI 96822**

TITLE OF STUDY:

An exploratory study: Native Hawaiian parents' perspective and experience caring for their children with asthma.

RESEARCH TEAM MEMBERS

Principal Investigator (PI): May Kealoha. Moderator

Research Assistant (RA): To be determined. Completes enrollment procedure (Demographic Survey, Informed Consent, Copy of Informed Consent, Incentive, and Receipt of Incentive), Note taker, clerical assistant, and in charge of audio-recording.

Professional Transcriptionist: To be determined. Transcribe audio recording verbatim.

STEPS

ONE MONTH BEFORE FOCUS GROUP DISCUSSION:

- PI will reserve focus group site(s).
- PI to meet with RA to review focus group procedures and RA's assignments.
- RA will begin to prepare the research packet. The research packet should include: participant letter, research informed consent form, participant demographic survey, thank you participation envelopes, participant incentive form (receipt of \$50 by participant), list of participants, name tents for participant, participant name tags, research team name tags, and site flyers.
- Flyer with information about the study will have been completed. Information to include purpose of study, focus group dates, times, and location, confidentiality assurances, and honorarium.

ONE WEEK BEFORE FOCUS GROUP DISCUSSION:

- PI to meet with RA to review focus group procedures, RA's assignments.
- RA to place completed research packets into locked storage in PI's office.

DAY OF FOCUS GROUP SESSION:

- Research team arrives for site visit at least two hours ahead to SET UP and PREPARE. RA: Hospitality table set up with refreshments. Arrange seating.

- The RA is responsible for obtaining the eligibility criteria, research informed consent form, and demographic survey from each participant before the start of the focus group. This takes approximately 10 to 15 minutes for each participant.
- After the research informed consents and participant demographic surveys have been signed and/or filled out, RA1 will ask participants to sign for receipt of the \$50.00 honorarium.
- RA Note taker fills out the Participant List form, which includes code number, participant name, and comments.
- RA should have NAME TAGS for research team and participants. If tables are used, participants should have NAME TENTS with their names.
- PI to ask participants to sit in a circle.
- RA Note taker turns on two recorders and signals Moderator to Start.
- RA Note taker makes a diagram of the sitting arrangement and assigns a code number to participant that is the same as is the number on the demographic survey.
- Moderator leads focus group session.
 - Introduce research team
 - Purpose
 - What the study is about
 - Introduce the digital recorder
 - Purpose of name tents or name tags
 - Purpose of moderator
 - Expectations of participants
 - Set Ground Rules
 - Introduction of participants to others in focus group
 - Begin Questions. 10 minutes per question. Total of 8 questions, for total of 80 minutes
 - Ask if there is anything else to share
 - Summarize the main points and ask if this summary is accurate
 - Asks if we missed anything?
 - Moderator thanks the group for their participation

AFTER FOCUS GROUP SESSIONS:

- RA responsible for cleaning refreshment area and rearranging furniture.
- RA note taker responsible for turning off digital recorder and cleaning recording area.
- PI responsible for preparing a written summary of key points.
- PI leads debriefing session.
- PI collects all information and two digital recorders in a sealed package labeled COMPLETED FORMS for return to PI Office.
- PI and RA clean area and pack supplies and equipment.
- Digital recordings are to be submitted to PI.

- PI creates two sets of CDs. One CD is to be used to transcribe discussion, and the other is kept in a locked box.
- Moderator will give one CD to Transcriber.
- Transcriptionist to transcribe the focus group discussion verbatim.
- PI receives the transcripts from Transcriber for analysis.
- PI arranges meeting with RA to discuss data analysis.
- PI is responsible for dissemination. Research team members will be acknowledged in the dissertation and all reports.

Note: Adapted from “Data Collection Protocol” by M. Kataoka-Yahiro and K. Richardson, 2009.
Adapted with written permission from authors.

Appendix K

Focus Group Protocol

**UNIVERSITY OF HAWAI'I at MĀNOA
School of Nursing and Dental Hygiene
Department of Nursing
2528 McCarthy Mall, Webster Hall
Honolulu, HI 96822**

TITLE OF STUDY:

An exploratory study: Native Hawaiian parents' perspective and experience caring for their children with asthma.

1. Welcome	Welcome. I want to thank you for coming today. My name is May Kealoha and I will guide today's talk story session. This is --- here to help us.
2. Opening Introductions (5 minutes)	<p>Open prayer (pule) if appropriate and acceptable to participants.</p> <p>Let's introduce ourselves to each other by sharing our name, family background, and area of your family home.</p> <p>My name is May Kealoha. I am a nursing student at the University of Hawai'i at Mānoa. My father's name was Bironio and he was born in Waimea, Kaua'i. Later he was <i>hānai</i> to the Kealoha family in Koloa, Kaua'i. My mother is from Kumamoto, Japan. I live in Kaimuki with my one son. (Next person to introduce themselves.)</p>
3. Ground Rules (5 minutes)	<p>Before we begin I need to explain the ground rules for our discussion.</p> <ol style="list-style-type: none"> a. I am going to ask you several questions. We do not have to go in any particular order but we do want everyone to take part in the discussion. We ask that only one person speak at a time. b. This is a talk story time so you can listen and talk to each person. You may agree or disagree what is being said. There are no right or wrong answers. We are asking you for your <i>mana'o</i> (opinion) based on your own personal experiences. We are here to learn from you. c. Don't worry about having a different <i>mana'o</i> (opinion) than someone else. But please do respect each other's answers or opinions. d. If there is a particular question that you do not want to answer, you don't have to answer. e. We will treat your answers as confidential. We are not going to ask for anything that could identify you and we are only going to use first names during the talk story session. <p>We also ask that each of you respect the privacy of everyone in the room and not share or repeat what is said here in any way that could identify anyone in this room.</p>

	<p>f. We are audio-recording the discussion today and also taking notes because we don't want to miss anything you say. However, once we start the digital recorder, we will not use anyone's full name and we ask that you do the same. Is everyone OK with this session being audio recorded? (GET VERBAL CONSENT TO AUDIO RECORD DISCUSSION. IF A PARTICIPANT DECIDES THAT HE DOES NOT WANT TO BE RECORDED AND WANTS TO LEAVE, THE PESON SHOULD STILL BE GIVEN THE ENTIRE HONORIUM.)</p> <p>g. We will not include your names or any other information that could identify you in any reports we write. We will destroy the notes and audiotapes after we complete our study and publish the results.</p> <p>h. Finally, this discussion is going to take about 1 1/2 hours and we ask that you stay for the entire meeting. We have given you an honorarium of \$50 and bags of fresh <i>poi</i> to thank you for participating.</p> <p>i. What questions do you have?</p>
<p>4. Introduction – for recording purposes (5 minutes)</p>	<p>(Start audio recording now.) I'd like to go around the table starting on my right and have each person say your name again. Please tell us your first name only and the name of your child or children with asthma.</p>

<p>5. Group Discussion - Question 1 (10 minutes)</p>	<p>Question 1: When did it (illness/asthma) start? PROBE: How did you know that your child had asthma?</p>
<p>6. Group Discussion - Question 2 (10 minutes)</p>	<p>Question 2: What do you do to care for your child with asthma? PROBE: What do you do to help your child every day and during illness?</p>
<p>7. Group Discussion - Question 3 (10 minutes)</p>	<p>Question 3: What things or people have made it easier for you as a parent caring for your child with asthma?</p>
<p>8. Group Discussion - Question 4 (10 minutes)</p>	<p>Question 4: What things have made it harder for you as a parent? PROBE: What kind of <i>pilikia</i> (trouble) do you have taking care of your child with asthma?</p>
<p>9. Group Discussion - Question 5 (10 minutes)</p>	<p>Question 5: What is it like for you as a parent taking care of your child? PROBE: What is it like to be <i>makua</i> for your <i>keiki</i>?</p>

10. Group Discussion – Question 6 (10 minutes)	Questions 6: How do you manage caring for your child with asthma?
11. Group Discussion - Question 7 (10 minutes)	Question 7: How has your Hawaiian culture influenced you in the care of your child? PROBE: What healing practices have you learned from your elders (<i>kūpuna</i>) that you use for your child with asthma?
12. Group Discussion - Question 8 (10 minutes)	Question 8: What matters most to you as a parent about this illness or treatment? PROBE: Please share your <i>mana‘o</i> (thought/opinion) with us about caring for your child with asthma.

13. Final Thoughts (5 minutes)	Those were all of the questions that I wanted to ask. Is there anything else that anyone wants to share?
14. Review and Wrap-up (5 minutes)	I would like to summarize the main points that I learned from this session. -----. Is this summary accurate? Did I miss anything? Thank you for coming today and for sharing your experiences with us. We hope you enjoyed the talk story time today. Turn off audio recording.
15. Closing prayer	Closing prayer (<i>pule</i>) if appropriate and acceptable to participants.

Note. Adapted from “Focus Group Protocol,” by M. Harrell and M. Bradley, 2009, *Data Collection Methods: Semi-structured Interviews and Focus Groups*. pp. 124-125. Copyright 2012 Reproduced with permission of RAND CORPORATION in the format Dissertation via Copyright Clearance Center.

Appendix L: Recruitment Flyer

The University of Hawai‘i is conducting a study:

Mālama nā makua i nā keiki me ka hānō:

**Native Hawaiian Parents Caring for
Their Children with Asthma**

**Are you a Native Hawaiian mother or father?
Has your doctor told you that your child has asthma?
Is your child between 0 and 18 years old?**

If the answers are **YES**...

May Kealoha, RN and PhD student, would like to invite you to participate in a research study.

The purpose of this study is to learn what it is like for you as a Native Hawaiian parent to have a child (*keiki*) with asthma. Your participation may help nurses, doctors and others to better understand what it is like for Native Hawaiian parents to care for a child with asthma.

- One (1) focus group “talk story” session will take place at _____.
- Study volunteers will be compensated up to \$50 for their time.
- A summary of the results of the focus group session will be available to study volunteers.

To learn more about the study,

Please call May Kealoha, RN, at 808-734-9301

Appendix M

Pre-Group Checklist

1. Up-to-date copy of Interview Guide
2. Recruitment-related Items
 - a. List of names of participants
 - b. Payments of honorarium
 - c. Receipts for honorarium
 - d. Cooler and fresh poi
 - e. Consent forms
 - f. Name tents
 - g. Name tags
 - h. "Focus Group Here" directional signs
3. Taping
 - a. 2 digital recorders
 - b. Batteries or power cords for recorders
4. Writing-related Items
 - a. Pencils and pens
 - b. Index cards
 - c. Markers
 - d. Easel and pads
5. Refreshments
 - a. Paper products: plates, napkins, cups, fork, spoons
 - b. Fruit platter
 - c. Water cooler, ice, water
6. Miscellaneous
 - a. Clock
 - b. Masking tape
 - c. Facial tissue

*Appendix N***Informed Consent Form**

**UNIVERSITY OF HAWAI'I at MĀNOA
School of Nursing and Dental Hygiene
Department of Nursing
2528 McCarthy Mall, Webster Hall
Honolulu, HI 96822**

Research Informed Consent Form**TITLE OF STUDY:**

An exploratory study: Native Hawaiian parents' perspective and experience caring for their children with asthma.

PRINCIPAL INVESTIGATOR:

May Kealoha
Doctoral Student
University of Hawai'i at Mānoa
School of Nursing and Dental Hygiene
Department of Nursing
2528 McCarthy Mall, Webster Hall
(808) 734-9301

CO-INVESTIGATOR:

Dr. Merle Kataoka-Yahiro
Associate Professor
University of Hawai'i at Mānoa
School of Nursing and Dental Hygiene
Department of Nursing
2528 McCarthy Mall, Webster Hall 409
(808) 956-5329

INTRODUCTION:

My name is May Kealoha. I am a doctoral student at the University of Hawai'i at Mānoa (UH) in the School of School and Dental Hygiene. As part of the requirements for earning my doctoral degree, I am doing a research project. The purpose of my project is to learn about Native Hawaiian parents' perspective and experience caring for their children with asthma. I am asking you to participate because you have a child with asthma.

This Informed Consent Form is to explain the research and the how the participants will take part in the research. We want to share with you first what the research is about, who will take

part, what will be asked of participants, and your rights. This presentation is called informed consent.

After you understand the purpose and what will be done in the research, you will be asked if you are willing to take part in the research study. If you agree to take part in the research, you will be asked to sign the Informed Consent Form.

A signed copy will be given to you to keep so that you can have a written description of what the research is about.

You have the freedom to decide whether you will participate in the research or not.

- Taking part in this study is of your own free will.
- You may decide not to take part in the study.
- If you decide to participate in the research but later change your mind, you may stop at any time without any problem or penalty.
- If you decide that you don't want to be part of this study, you can leave the room at any time.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the research is for other people, especially doctors and nurses, to know what it is like for you as a Native Hawaiian parent to have a child (*keiki*) with asthma.

HOW LONG WILL YOU BE IN THE STUDY?

You will be asked to sit and “talk story” with other Native Hawaiian parents who have a child with asthma. It will take about 1 1/2 hours.

You will also be asked to fill out one questionnaire with your name, address, child's name, child's birth date, and other information. It will take about 10 minutes to complete.

You will be asked to attend another group meeting 2-3 weeks after the “talk story” session. This meeting will be about 15-30 minutes. The purpose of this meeting is to share the researcher's recording of the “talk story” with you. The researcher would like to know from you if the information recorded was correct and complete.

WHAT WILL YOU BE ASKED TO DO IN THE STUDY?

You will be asked to sit and “talk story” (focus group) with 3-5 other Native Hawaiian parents who have a child (*keiki*) with asthma. The purpose of the research is to learn what it is like for Native Hawaiians parents to have a child (*keiki*) with asthma. A researcher will ask 8 questions, and each participant will have the opportunity to talk or listen. While everyone is talking and listening, one researcher will also be listening and writing notes about what people are saying. In order to get everyone's words on paper, a digital recorder will be turned on during the “talk story” time. You may leave at any time during the “talk story” session without any problem or penalty. We are grateful for your help.

WHAT ARE THE FORESEEABLE RISKS OR DISCOMFORTS?

The study will take about 2 hours of your time and you will be sharing your thoughts with others (loss of privacy).

WHAT ARE THE BENEFITS?

You will receive no direct benefit from participation in this study, but your participation may help nurses, doctors and others to better understand what it is like for Native Hawaiian parents to care for a child with asthma. We may ask Native Hawaiian parents in other areas of Hawai‘i about their experiences in another research project. Our community will be enriched by the information that you and the other parents share with us. Long range benefits may be that nurses and doctors will be able to take better care of Native Hawaiian families who have a child with asthma.

WHAT ARE THE ALTERNATIVES TO BEING IN THE STUDY?

You do not have to participate in the study.

WILL YOUR INFORMATION REMAIN CONFIDENTIAL?

When I type and report the results of my research project, I will not use your name or the name of your child or any other personally identifying information. Rather I will use numbers instead of names and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.

The research team will listen to the digital recorder and read their notes. They will write what they learn in a paper that will be published so that our community and people of Hawai‘i will know what it is like for Native Hawaiian parents to have a child (*keiki*) with asthma. Also the research project will be shared with interested people such as doctors, nurses, research institutions, and state and federal organizations.

The digital recording of the “talk story” session will only be used for the purpose of this research. The digital recordings will be kept in a secured double locked file cabinet in the principal researcher’s office. The recordings will be kept for the duration of the research project only. After the research paper is written then the digital recordings will be destroyed.

ARE THERE ANY ADDITIONAL COSTS TO YOU?

None

WILL YOU BE PAID FOR YOUR PARTICIPATION?

If you decide to participate in the study, you will receive \$50.00 and 2 bags of fresh *poi*. We give this gift to you in appreciation for your time, your *mana‘o*, and *kōkua*.

YOU HAVE THE RIGHT TO REFUSE OR WITHDRAW FROM THE STUDY

You may agree to participate or refuse to participate in the research. You may decide to stop participating at any time. There is no penalty or loss of benefit or taking away of our token of appreciation. If you decide to stop participating, the information that was collected from you will be kept as part of the research. No action will be taken to complete the research with you.

You have the right to refuse to sign this Informed Consent Form. Your refusal to sign this Form means that you cannot participate in this study.

WHO DO YOU CONTACT WITH QUESTIONS?

This study has been explained to you by the research investigators. If you have any other questions about this study, you may call May Kealoha, Principal Investigator, at (808) 734-9301 or Dr. Merle Kataoka-Yahiro, Co-Investigator, at (808) 956-5329. If you have any questions about your rights as a research participant, you may contact the Committee on Human Studies, University of Hawai'i, 1960 East-West Road, B-104, Honolulu, HI 96822 by phone @ 808 956-5007 or email at uhirb@hawaii.edu.

VOLUNTARY CONSENT STATEMENT:

I HAVE READ THE INFORMATION PROVIDED AS WRITTEN IN THIS PAPER. I HAVE BEEN GIVEN THE OPPORTUNITY TO ASK QUESTIONS ABOUT MY PARTICIPATION IN THIS STUDY, *NATIVE HAWAIIAN PARENTS CARING FOR THEIR CHILDREN WITH ASTHMA*. I VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

YES, I AGREE TO BE RECORDED IN THE TALK STORY SESSION

NO, I DO NOT AGREE TO BE RECORDED IN THE TALK STORY SESSION

My signature below indicates that I agree to participate in this research project.

Participant's Name (Print)

Date

Participant's Signature

Date

Signature of Investigator

Date

A SIGNED COPY OF THIS INFORMED CONSENT FORM WILL BE GIVEN TO ME.

Appendix O

Organization of Results: Uncertainty in Illness Theory

Table O1

Construct, Category, Subcategory: Stimuli Frame and Structure Providers

Construct	Category	Subcategory	Focus Group Question
Stimuli Frame	Symptom Pattern		1. When did it (illness/asthma) start?
	Event Familiarity	<i>Asthma Experience*</i> <i>Asthma Triggers*</i> <i>Health Care System</i>	2. What do you do to care for your child with asthma?
	Event Congruency		
Cognitive Capacities			
Structure Providers	Credible Authority		3. What things have made it easier for you as a parent caring for your child with asthma?
	Social Support		
	Education		4. What things have made it harder for you as a parent?

Note. New subcategories are bolded and indicated by *.

Table O2

Construct, Category, Subcategory: Uncertainty, Appraisal, Adaptation

Construct	Category	Subcategory	Focus Group Questions
Uncertainty	Lack of Information Unpredictability Complexity Ambiguity		5. What is it like for you as a parent taking care of your child?
Appraisal: Inference of Danger	Coping Mobilizing Strategies Affect Control Strategies	<i>Vigilance</i> <i>Information Seeking</i> <i>Direct Action-Western*</i> <i>Complementary & Alternative Medicine*</i>	6. How do you manage caring for your child with asthma? 7. How has your Hawaiian culture influenced you in the care of your child?
Appraisal: Illusion of Opportunities	Buffering Strategies		
Adaptation	Goal Directed Adaptation Difficulty		8. What matters most to you as a parent about this illness or treatment?

Note. New subcategories are bolded and indicated by *.

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