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Energy Webs and Nursing Praxis: Patterning in the Lived Experience of Type 2 Diabetes

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ENERGY WEBS AND NURSING PRAXIS:

PATTERNING IN THE LIVED EXPERIENCE OF TYPE 2 DIABETES

Systems Change Project
Submitted in Partial Fulfillment
Of the Requirements for the Degree of
Doctor of Nursing Practice

St. Catherine University
St. Paul, Minnesota

Karen Marcus Glasenapp

December 2010

ST. CATHERINE UNIVERSITY
ST. PAUL, MINNESOTA

This is to certify that I have examined this
Doctor of Nursing Practice systems change project
written by

Karen Marcus Glasenapp

and have found that it is complete and satisfactory in all respects,
and that any and all revisions required by
the final examining committee have been made.

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25 November 2010

DEPARTMENT OF NURSING

DEDICATION

This DNP systems change project is dedicated to those living with diabetes daily and to their families whom I have been privileged to know over the years. They have generously shared their stories, their *webs,* and have graciously welcomed me as a partner on their diabetes journeys. They are the reasons that I have a deeper understanding of *health as expanding consciousness* and why I remain dedicated to the essence of nursing in diabetes care engagement.

ACKNOWLEDGMENTS

At its inception this DNP systems change project, *Diabetes Energy Webs and Nursing Praxis,* seemed an elusive vision. True collaborative efforts nudged the vision to fruition. It is my honor to acknowledge those who played an integral role in its evolution:

- My husband Doug, an anchor of patience and encouragement, whose own experiences confirm that caring truly is the *moral imperative of nursing*…
- My 3 sons, Logan, Tim, and Steve, who keep me grounded and challenged…
- My mom and dad who have grown gracefully into 82 years of life. They were my early teachers of commitment, justice, and compassion…
- My brother and sisters who are lifelong companions in the creating and telling of stories, and in strengthening webs of connections…
- My advisor, mentor, and spirited companion along the journey, Dr. Maggie Dexheimer Pharris, who is a living exemplar of the pure giftedness of nursing and who taught me that *when the old rules no longer apply it's time to create new ones…*
- My site mentor and critical friend Pat Schroeder, who lives with strength, humility, and grace, and who has been a dynamic influence to my nursing career…
- My attentive reader and gentle soul, Dr. Kathleen Kalb, for always speaking with affirmation, optimism, and joy…
- My DNP student colleagues, especially Judy Peters, Mary Sinnen, and Michelle Spadoni, who shared every peak and valley of the past 2 ½ years…

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Executive Summary

Diabetes is an illness best described as costly, complex, chronic, and epidemic in the United States, affecting nearly 24 million children and adults; 90% of who have type 2 diabetes (Centers for Disease Control and Prevention, 2008). On average, every 20 seconds in the United States, an individual 20 years of age and older receives a diagnosis of diabetes; yet, an estimated 6 million people with the disease remain undiagnosed (American Diabetes Association, 2010b). The financial burden of this disease, the inconsistent effectiveness of well-intentioned diabetes programs to educate and actualize change behavior, and the limited resources of millions of Americans give testimony to the need for a paradigm shift in diabetes care. Nursing is called to envision and actualize this paradigm shift. Using a hermeneutic dialectic approach based on a unitary transformative perspective as described by Margaret Newman in her theory of health as expanding consciousness (1994), this Doctor of Nursing Practice research project is an inquiry into the potential benefit of approaching "diabetes care" through nursing praxis. "There is a need for a shift from…eliminating the problem to the more inclusive perspective of helping people recognize the meaning of their lives when disease occurs" (Newman, 2008, p. 2). The *Energy Web* resulted as an emergent method and served as a visual tool that guided efforts to identify and enhance pattern recognition for both the nurse researcher and the participant. Use of praxis to illuminate choice points, the treasures and trappings in the lived experience of type 2 diabetes, to inform nursing practice opens possibilities of a transformative potential toward diabetes care engagement.

Energy Webs and Nursing Praxis:

Patterning in the Lived Experience of Type 2 Diabetes

“Diabetes *Energy Webs* and Nursing Praxis” is an example of advanced practice nursing, drawing upon the tenets of social justice and guided by the theoretical underpinnings of health as expanding consciousness (Newman, 1994) to partner with individuals affected by diabetes. This collaboration evolves to a greater understanding of the lived experience of type 2 diabetes and may begin to transform the philosophical approaches from a “healthcare delivery model” to that of a “care engagement model” fostering effective self-care, ongoing safety and freedom in dialogue, and genuine hopefulness through individual, family, and community empowerment.

A strong intuitive sense suggests that the answers to this “metabolic epidemic” lie in the life patterns of those with type 2 diabetes and if invited, they would be willing to give voice to their experiences. This project is intended, not to develop a novel approach to “chronic disease management,” but rather to simply utilize a nursing based theory, in partnership with the study participants, to move to a greater understanding of the lived experience of type 2 diabetes through pattern recognition and nursing praxis. This project is an opportunity to illuminate nurse care as the moral imperative of our discipline especially in the face of the challenges of type 2 diabetes. In the spirit of the unitary transformative perspective, where the nature of reality is one indivisible whole and the nature of change is simultaneous and not always predictable (Newman, Sime, & Corcoran-Perry, 1991), the engagement model holds possibilities for unforeseen meaningful change for nurse and patient alike.

We know that concepts of diabetes "management" and "non-compliance" are antiquated and patronizing at best, detrimental and self-defeating at the worst. The stories that are the center of this work transition the focus of diabetes care from "blood glucose control" and rigid food plans to self-recognition of individual life experiences that weave patterns of choice points. Life events may not be as significant as our response to those events. As individuals and as communities, there is a call to begin a movement away from self-deprecation and the familiar "blame-guilt-shame" triad of traditional diabetes "management," toward a diabetes care engagement approach, acknowledging the significance and complexities of each individual "web" as it gives meaning to the collective *Energy Web* of type 2 diabetes.

Background and Significance of the Project

Diabetes: The Scope of the Problem

Type 2 diabetes is an acquired metabolic-neuro-endocrine disorder currently understood to be a result of converging forces of insulin insufficiency, insulin resistance, and incretin deficiencies (Edelman & Henry, 2007). It is greatly impacted by lifestyle strategies and environmental factors. Once a disease that almost exclusively targeted the "elderly," type 2 diabetes is now affecting children and adolescents, as well as adult and senior populations of every ethnicity; it poses a major public health problem across the nation.

In 2007 there were 1.6 million new cases of diabetes diagnosed in the U.S. population aged 20 years or older (Centers for Disease Control and Prevention, 2008). If trends in the disease continue as they have, those with diabetes will lose an average of 10-15 years of life and this may affect as many as one of every three people in the United

States. Diabetes is primarily responsible for the new cases of renal failure, blindness, and non-traumatic lower-extremity amputation in adults. (Centers for Disease Control and Prevention, 2010b).

Type 1 diabetes differs from type 2 in many respects and although the causes of type 1 are not clearly understood, there is an absolute insulin deficiency and supplemental insulin is a necessity. Type 1 diabetes is an auto-immune disease, is not believed to result from a lack of “self-care,” and accounts for approximately 5%-10% of all cases of diabetes (National Institute of Diabetes and Digestive and Kidney Diseases, 2008). Type 2 diabetes is an acquired disease with numerous contributing factors currently known, including heredity, obesity, inactivity, poor nutrition, and situational stress and therefore is often associated with questionable self-care practices. Tragically in the majority of the cases, type 2 diabetes is preventable yet despite valuable and convincing research, relatively few dollars are effectively placed into diabetes prevention.

Evidence-based research continues to wave the obvious flag of prevention as a means to slow the progression of this epidemic in the United States. The American Diabetes Society leads the commitment to reduce the burden of diabetes (American Diabetes Association, 2009b). Health care providers across the country recognize the significance of the disease and its impact on individuals and families; yet, a sense of frustration pervades the daunting task of integrating national diabetes guidelines and “changing patient behaviors.” It is clear that “best efforts” are falling short, resulting in legislators, healthcare systems and providers, large employers, and third party payers gathering on one side of the “no-win” blame game with the type 2 diabetes population on the other.

"Making Systems Changes for Better Diabetes Care" (National Diabetes Education Program, n.d.) is a project that was initiated by The National Diabetes Education Program in response to the recommendations of the 2001 *Crossing the Quality Chasm* report to the National Institute of Medicine. The focus is to support health care professionals to make a difference in preventing and treating diabetes. It addresses patient-centered care utilizing a true team-approach. The ideas are extensive and precise and yet the degree to which they are being integrated by educators and providers is unclear. Interestingly, this web site was last updated in January, 2007 suggesting questionable investment.

The Unspoken Realities

The tangled web of achieving diabetes wellness is an exhausting and complex venture complicated by current economics in a broken healthcare system. It is now anticipated that one of every three children currently born in the United States will acquire diabetes in their lifetime. If that child is of a minority population, his or her risk is increased to a one in two chance (National Kidney Foundation of Wisconsin and Wisconsin Lions Foundation, 2008). An estimated 44 million people in this country have no health insurance, and another 38 million have inadequate health insurance (HealthReform.GOV, 2010).

Without insurance people will pursue fewer office visits, decrease or stop their medication, or put off routine or annual exams. This population is at higher risk for accessing care in systems ill-equipped for chronic disease management such as Urgent Care or Emergency Room settings. For individuals and families, the cost of diabetes often renders treatments inaccessible. About 25% of American households affected by diabetes will incur healthcare costs the equivalent of 10% or more of the total household income. This results in avoidance of suggested healthcare for one in six people with diabetes (HealthReform.GOV, 2010).

The answers for successful diabetes control have been eluding health care providers and therefore may lie beyond the evidence-based guidelines and the structured diabetes education curricula. Perhaps healthcare professionals, instead of ascribing to the narrow and intense focus on “glycemic control,” may find value in stepping back only to step into the disease through those living it. Perhaps the missing link in diabetes management is not “managing” at all, but rather simply withholding judgment and intervention in order to be respectfully present to those on their journey and responsive to needs as they arise. Glycemic control is critical in limiting microvascular complications and in contributing to a favorable quality of life; however, when best efforts are failing, there can be no harm in targeting the same outcomes but rerouting efforts through alternate approaches.

Opportunities for Exploration

“Energy *Webs* and Nursing Praxis: Patterning in the Lived Experience of Type 2 Diabetes” explores rich, complex lives and the articulate, sometimes pain-filled voices in an effort to simply be present and begin to understand the life experiences of those with type 2 diabetes. This Doctor of Nursing Practice (DNP) endeavor is a search for the “disconnect” prevalent in diabetes care. Many patients are challenged to adopt the research-defined “healthy behavioral lifestyle strategies” that contribute to diabetes risk reduction. Nursing caring, grounded in Newman’s (1986, 1994) theory of health as expanding consciousness (HEC), has tremendous potential to impact the lives of those affected by type 2 diabetes and the nurses who journey with them.

The Tenets of Social Justice

"*Without a clear sense of our nursing identity and the meaning of our mission to society, we have no value or purpose other than to support and promote the practice of medicine.*" (Newman, Smith, Pharris, & Jones, 2008, E25)

Nursing for Social Justice (Kalb, 2009) is integral to this DNP project in the hope for the preservation or restoration of human dignity in the lives of those with type 2 diabetes. The Doctor of Nursing Practice change project is rooted in commitment to the *Code of Ethics for Nurses with Interpretive Statements* (American Nurses Association, 2001) with the original version dating back to Florence Nightingale's pledge of 1893. The current Code and the nursing profession exist as the result of evolution, transition, criticism, and growth. Interpretive statements of the Code, developed by American Nurses Association (2001), serve as guideposts for advanced practice nurses, enhancing nursing care that is concordant with the ethical underpinnings of the profession (Fowler, 2008).

Social justice is an ethical principle that calls us to remain attentive to those not among us, with those who are marginalized, and it mandates that inequalities be addressed. As nurses we accept the moral imperative to advocate, in all circumstances, for the well-being of the poor and the marginalized. Included in this call is a commitment to distributive justice that ensures the burdens and benefits (food, education, health care, etc.) of a community, society, or culture are evenly distributed across that system (Grace, 2009). The challenge is to identify all inequalities specific to diabetes care in our communities and to bring restorative healing. The tenets of social justice anchor individuals in their lives and in their communities and serve to guide diabetes nursing care. When social justice is threatened and/or violated, there are challenges to the implicit and explicit order of individual "webs" and living well with diabetes becomes elusive.

Health Disparities and Health Inequities

Health disparity refers to a health variance among groups of people and may be inevitable because of genetics or biological characteristics. In comparison, health inequities result from social policies or economic environments and, in essence, are considered unfair because they are not inevitable (University of Wisconsin, 2010b). Although type 1 diabetes is more prevalent in children and adolescents, the incidence of type 2 diabetes is increasing in this age group, especially for people of color and poor people. Obesity rates are climbing; sedentary lifestyles are more common; and there is evidence of poor nutrition with diets high in fat, calories, and processed foods. In underserved communities there is limited access to large grocery stores offering reasonably priced fresh produce and options for healthy nutrition; yet, there is a surplus of corner markets that sell nutritionally poor foods. Compounding the problem is the lack of safe outdoor environments for exercise or activities in these communities (National Kidney Foundation of Wisconsin and Wisconsin Lions Foundation, 2008). The social determinants of health inequities in diabetes are becoming evident.

There is a two-fold increased chance of developing the disease for those of African American, Native Alaskan, American Indian, and Hispanic heritage. Over 30% of Hispanics are uninsured. One of every four African Americans is without a primary care provider. Minority communities are negatively affected to a greater extent than non-

Hispanic Whites because of a lack of disease specific education. Diabetes complications are more common among African Americans and Hispanics (U.S. Department of Health and Human Services, 2008). When services and supplies are limited or not affordable, patients stop self-monitoring blood glucose or discontinue diabetes medications. Routine follow-up visits with primary care providers decrease or stop. The downstream costs of potential complications such as retinopathy, neuropathy, or nephropathy are increased exponentially in comparison to the cost of routine care (American Diabetes Association, 2009b).

The links between hypertension, sedentary lifestyle, and obesity are associated with neighborhood safety, access to healthcare, financial status, and nutritional habits. For example, people in affluent neighborhoods with low crime rate and safe green space are afforded opportunities for increased exercise, have decreased fear as a situational stressor, and are less likely to have diabetes (National Kidney Foundation of Wisconsin and Wisconsin Lions Foundation, 2008). Issues of healthcare disparity and inequities enter ethical discussions as do concern for access to quality health care. Work generated by the University of Wisconsin Population Health Institute (2010b) suggests that our communities themselves, and the quality of life afforded in those communities, are primarily responsible for the health of the community. Factors of green space, safe walking spaces, low threat of crime, and low unemployment favorably impact communities in their health status. Neighborhoods where markets with fresh fruit and vegetables outnumber liquor stores may have greater health outcomes and health factors. This supports the commitment to improving the health of our community through programs and policies (University of Wisconsin, 2010a). The inequities shroud an already complex disease and the old rules are no longer working. HEC may begin to unveil the intricate nature of the unique experiences amidst the inequities.

There is strong support for the value of formal diabetes education programs certified by the American Diabetes Association (ADA). The ADA offers data supporting the value of the programs in helping individuals achieve targets, self-manage diabetes, and deter complication development (American Association of Diabetes Educators [AADE], 2009a). The literature also suggests program under-utilization and less than convincing outcomes. A lack of distributive justice is at every turn of the diabetes education programming controversies. Duncan, et al. (2009) analyzed data from over nine million administrative claims and identified 634,645 individuals with diabetes who participated in formal diabetes education programs. The study results suggest, as other studies concluded previously, diabetes education is directly linked with lower hospitalizations, lower use of emergency services, and an increased use of prevention services. Those who received formal diabetes education when compared with those who did not, were female, younger, and more affluent; and they had lower clinical risk, higher adherence to diabetes standards of care, and lower average costs.

There are questions that loom regarding provider bias with respect to investment in individual patients, patient populations, and diabetes education programs specifically. Is there a bias that influences which patients are referred for education and which are not “good candidates”? The study by Duncan et al. (2009) leads to questions regarding whether or not there is bias in the patient selection for education programming, suggesting that it is the patients who are more likely to be “compliant” with the educational recommendations, those who have insurance coverage for the services, and those without barriers to accessing diabetes education who indeed participate in the service. Noted as a limitation of this particular study is the possible bias that perhaps patients who are already compliant are more likely to seek out and receive diabetes education. Without referrals or access to the education programs, the underinsured and vulnerable populations are therefore denied access to quality care.

Hope on the Horizon?

In early October 2010, the U.S. Department of Health and Human Services (2010a) announced that grants in excess of 727 million dollars were awarded to 143 health centers in the United States. This Affordable Care Act money is expected to enhance quality and access to health care and to increase services for an anticipated 745,000 underserved patients. There is clear anticipation that a majority of the money will be spent on new construction and building renovations. This money is in addition to the two billion dollars already invested in community health centers through the American Recovery and Reinvestment Act (U.S. Department of Health and Human Services, 2010b). Opportunity to enhance diabetes care cannot be lost with this financial endowment to clinics serving the underserved across the country.

At this time of heightened attentiveness to healthcare reform, the ADA remains integrally involved in offering recommendations for a comprehensive approach to reduce the burden of diabetes and its complications. Suggestions center around improving access to care, ensuring quality care that is affordable, reducing ethnic inequalities, increasing achievement of delineated outcomes, and controlling costs. Early intervention to prevent disease development and/or diagnose existing disease is critical (American Diabetes Association, 2009a).

Issues however go beyond access to quality care and this is one major disconnect in the world of diabetes care. An estimate generated from a review of facts and figures out of the Centers for Disease Control (CDC) indicates that only 10% of good health is attributable to health care. A staggering 90% of good health results from community and environmental factors such as employment, education, social support, racial equality, and associated factors. Considered upstream health determinants, realities of food security and accessibility, community violence, and limited transportation impact the well-being of individuals (Wisconsin Center on Health Equity, n.d.).

Inherent in this concept are health policy issues that are expansive and exhausting contributing to "clinical inertia" (Shah, Hux, Laupacis, Zinman, & van, 2005). Clinical inertia describes a condition that affects healthcare providers. Although they are attentive and concerned and take some measures to move toward achieving outcomes, there is a lack of consistent effort to actually achieve those outcomes. For a number of reasons health care providers lack "stick-to-it-iveness" in guiding patients toward identified national guidelines for clinical indices such as lipid goals, blood pressure target, or optimal estimated average glucose levels.

Some suggestions as to the etiology of clinical inertia include problems with healthcare providers, with the healthcare systems, and with patients themselves. Plausible problems include healthcare professionals lacking awareness of the standards; poor communication of, or acceptance of, the guidelines or established outcomes; and busy practices with not enough systems in place to support the work. Inertia on the part of healthcare professionals is argued to be a problem with the patients and not the fault of the healthcare professionals. Patient unwillingness or inability to adhere to recommended medical regimens is seen by providers as solely due to the financial costs involved or because of apathy or lack of understanding on the part of patients.

The second report of the Committee on the Quality of Health Care in America (Institute of Medicine, 2001) was prepared to address the gaps in quality care in America, detailing misuse, overuse, and underuse as the three quality problems. Attention is given to elimination of errors, avoidance of preventable complications, and equal distribution of health care benefits to all people. The goal is to establish an equitable, humane, patient-centered system that is respectful of individuals. There is illumination of the health care inequities involving race, ethnicity, socioeconomic status, or location of residence (Institute of Medicine, 2001). There are compelling arguments suggesting that if we are to be successful in reducing health inequities, "upstream determinants of health" need to be impacted to effectively reduce disease development (Wisconsin Center of Health Equity, n.d.) and practices of clinical inertia need to be addressed and abolished (Shah et al., 2005).

"The effectiveness of treatment is heavily influenced by where people live and their relationships with those with whom they live" (Mason, Leavitt, & Chaffey, 2007, p. 250). Our living, school, and work environments; our daily habits; and our friends, family, and neighborhood culture all impact a sense of well-being. Individuals are products of their environment and the interaction between humans, health, and the environment is a dynamic relationship (Newman, 1994). The field of public health illuminates the fact that "social rather than medical interventions make a far greater contribution to the health of any community" (Mason et al., 2007, p. 250). Nurses becoming involved in the lives of those with diabetes will begin to impact the face of this disease by affecting the upstream variables. As healthcare providers hear, understand, and appreciate the individual *Energy Web*s and their evolving patterns, there is the hope that the inequities and inertia in healthcare may become less problematic.

Assumptions

This DNP project evolved from a dedication to those affected by type 2 diabetes and to the nurses who care for them, and from a number of personally held assumptions. These assumptions include the beliefs that individual patient faces and voices are missing in current diabetes management approaches and that the focus on behavioral change through the prescribed education as delineated in the American Diabetes Association curriculum may not be enough. Specific assumptions of this project are as follows:

1. Current diabetes management strategies are costly; energy investment to effect behavioral change is exhausting; and overall results demonstrate minimal effectiveness.
2. A second assumption is that our patients with diabetes have stories to tell and there are critical patterns embedded in those stories. Once illuminated, recognition and appreciation of these patterns will change the diabetes journey for patients and for nurses.
3. Lastly, the current visibility of nursing in this disease trajectory is called into question. When nursing becomes genuinely present in the lived experience of type 2 diabetes, the potential to move from diabetes management to diabetes care engagement is immeasurable.

Diabetes *Energy Web*: Weaving in Objectives

"*Energy Web*s and Nursing Praxis" is focused on hearing and understanding stories of the lived experience of type 2 diabetes. Ultimately the primary objective is the genesis of transformative thinking in the diabetes care delivery model through adoption of a new paradigm. The hope is to come to a collective understanding that type 2 diabetes is not about "control," "success," or "failure," but rather about the experiences in the lives of individuals and the opportunities to evolve as we encounter "choice points," to a greater understanding of health as expanding consciousness in diabetes.

Nursing praxis and the integration of HEC is a call to establish a "therapeutic presence" with our patients, the connection of mind, body, emotion, and spirit. Such a presencing is described as a *soulful* relationship resulting from being fully committed in the moment to the patient (Burkhardt & Nagel-Jacobson, 2002; Helming, 2009). For nursing, this involves the critical need to keep present in the chronic illness trajectory and to integrate the patterns imbedded in the experiences to make "caring in the human health experience" visible (Newman, Sime, & Corcoran-Perry, 1991). Koerner (2007) delineates the triad of nursing as science, art, and essence. Science is the work of the discipline involved in evidence-based practice, the evaluative piece concerned with the physical being. Nursing as art deals with discernment and pattern recognition. This is the intuitive aspect that is attentive to interpretation, the subtle non-verbal cues that offer insights, and the *background of the human landscape* (p.47). The essence of nursing refers to *the healing presence* where nurses *create space for individuals to connect with their souls, their inner wisdom,* where the power to heal is innate. This is the hallmark of the nurse-patient relationship, a partnership toward wholeness (Koerner, 2007).

Another objective of this project integrates nursing's responsibility to move into the social realities of communities and address outcomes more comprehensively through a social reformation perspective (Bekemeier & Butterfield, 2005; Browne & Tarlier, 2008). DNPs are called to step up, understand, and address individual responsibilities in health, barriers to quality care that are rooted in economics, issues of inadequate education, and socio-political agendas (Bekemeier & Butterfield, 2005). The *Code of Ethics for Nurses with Interpretive Statements* (American Nurses Association, 2001) with integration of the tenets of social justice and Catholic Social Teaching (Kalb, 2009) call nursing to minister to the physical, psychological, and spiritual needs of those insured, underinsured, and uninsured by assessing, diagnosing, and treating both body and spirit. The leadership aspect of the DNP systems change project is a call to look deeply into diabetes care in our individual patients, their families, and our communities. The leadership responsibility involves an attempt to fully understand the underlying political agendas and to keep forward focused anticipating opportunities to effect change. This objective is accomplished through integration of nursing theory—fully, consistently, and genuinely—into practice. Integrating health as expanding consciousness transforms nursing practice to praxis and ensures that nursing is *caring for* and *being with* rather than *doing to*.

The Social, Ethical, and Political Faces of Diabetes

Standard coverage for Diabetes Self-Management Education (DSME) is a prescribed 10 hour program approved by the ADA that is to be completed within the first year of diagnosis (AADE, 2009b), whether the patient exhibits readiness to learn or not. This education and training is provided by educators in ADA recognized programs. Any hours not used at the end of that first year are forfeited. After the first year, education and training is limited to two hours annually, although with extenuating circumstances additional time may be reimbursable. Initially, patients report being in denial or overwhelmed and not ready to take in all the information that is given to them. Often education is focused on complications and medications that the patients may not experience for years. The recommended immediacy of education may not be a realistic time frame given patients' pre-contemplative readiness for change (Prochaska & DiClemente, 1983). Given the disease trajectory, education provided on an as needed basis—as the patient demonstrates need and/or readiness—may be more beneficial.

Barriers in accessing quality diabetes education range from lack of programs in the communities, to healthcare provider inertia in making the referrals, to patient failure to attend scheduled programs. There may be failure on the part of the patient to follow up for the education as a result of any number of reasons which may include, but are not limited to: fear or uncertainty with respect to a new diagnosis, facility, or educator; patient frustration with culturally insensitive programs and educators; patient inability to pay for numerous education visits or accept financial responsibility as a result of limited Medicare benefit assignment; and lack of appreciation for the importance of timely self-care education and skills training.

Of concern is that while the political parties, and individuals themselves, continue to stand firm in their own camps with little negotiation or sincere effort at bipartisan work, the overarching healthcare system remains disadvantaged and those affected by diabetes are losing precious commodities: jobs, limbs, and life. Much of this is a result of a system that not only fails to advocate for them, but also fails to protect them. In truth these losses should be preventable! There is a call for individual healthcare providers and educators to become engaged in the healthcare reform process, advocating for comprehensive diabetes care, for the sake of our patients. “[N]urses and physicians should be lobbying for better environmental conditions, nutrition, education, and social supports for young families” (Mason et al., 2007, p. 250).

Theoretical Underpinnings

The goal is not to “untangle” the complex webs of diabetes-affected individuals but rather to recognize the individuals and their webs, honor them, and potentially transform as a result of them. Once it becomes evident that *the old rules aren’t working any longer* (Newman, 1994; Picard & Jones, 2005) nursing practice is transformed to a new world of possibilities with the integration of a nursing theory. It is critical that “nursing theory” dialectic be demystified and recognized as the essential foundation of a meaningful nursing practice, just as a care-planning guide is to the student nurse or a stethoscope is to the nurse in cardiac care.

Health as Expanding Consciousness (HEC)

Health as expanding consciousness (Newman, 1994) challenges nursing to let go of traditional thinking involved in “care-taking,” “curing,” and “treating disease” at the opposite end of the continuum from wellness. Rather, HEC envisions the *whole* of the person, the environment, and life experiences and looks at the choice points of illness that allow us to transcend to higher levels of knowing, of consciousness, and of being. “A health challenge creates an opening in time and space from which flow the inner feelings, hopes, intentions, expectations, memories, pain, and decisions that give depth and context to the person suffering” (Koerner, 2007, p. 15). When we invite HEC to guide our practice of diabetes care, we are present to our patients and stand “inside” their experiences in pattern recognition as our work encompasses the “whole” of patient-environment-community and “health as pattern of the evolving whole” (Newman, 1994, p. xix).

When our worldview is linear, such that health is considered the absence of illness or disease, we then believe that we need to avoid it or fight it. If we can’t control it, we are marginalized or perhaps we are judged as not being invested in our health. In a linear and dualistic world, health is viewed as the absence of disease. In this paradigm wellness is considered a commodity or a token of *good behavior* (Koerner, 2007).

Newman’s new paradigm is that disease is a manifestation of health; mind and body are not separate entities, but manifestations of the whole being; and disease and non-disease are manifestations of the interaction of the person and environment (1986, 1994). Disease fosters the chaotic energy breakdown that allows for the integration and movement towards new order. Nursing fosters a therapeutic, nonintervention-focused relationship and allows for new awareness, altering worldview and contributing to transformational steps.

Newman (1994) refers to the hermeneutic-dialectic approach to inquiry involving interpretation of dialogue despite differing views with the intent of finding common understanding through respectful insight. This moves the nurse-researcher-theorist from an objective outside-in approach to one of appreciating the phenomenon inherent in the lives of patients as disclosed in the richness of dialogue. To move to a greater understanding of pattern and phenomenon this methodology invites the dynamic interchange of perspectives voiced in a caring and respectful presence. This is “story telling” in the richest sense of the words. For those who are novices in the HEC theory of nursing, Table 1 is a lens into some of the prominent concepts of the theory, described in terms to facilitate theory integration into practice.

Table 1

Toward an Integration of Theory: Tenets of Health as Expanding Consciousness

TENET	DEFINITION	SOURCE
Art of Caring	An intentional relinquishing of control; the "letting go of the obsession with self, the surrender into being, the opening of the heart"	Newman, 1994. Moss, 1981, pp. 10-11.
Caring as a "Moral Imperative"	Caring for body and soul; it is something that "transforms us and all that we do…"; beyond the motions and tasks of the discipline and work day	Newman, 1994, p. 141
Choice Points	Disruptions, moments of unpredictability or chaos, that present the opportunity to evolve or move toward a higher level of being; turning points; the moments in time when there is realization that the "old rules no longer apply" and movement toward expanding consciousness is facilitated	Picard & Jones, 2005, p. 12; Young, 1976.
Complementarity of Health & Disease	Fusion of one point of view with an opposite viewpoint lends to the emergence of a new, "synthesized" point of view. Disappearing perception of duality viewing illness as health and disease as a "meaningful reflection of the whole."	Newman, 1994, pp. 6-7.
Consciousness	The ability of the system to interact with the environment. The informational capacity of the system-the human being; includes the cognitive and affective awareness; the interconnectedness of the entire living system; the physiochemical maintenance and growth processes; the immune system (Newman, 2008).	Bentov, 1978; Newman, 2008; Newman HEC website, retrieved 11/13/2010.
Correlates of Consciousness	Movement-Space-Time are identified as dimensions of expanding consciousness.	Newman, 1979, 2008.
Dialectic	An approach involving a common goal which is to arrive at a higher level of truth and understanding through the discussion of differing views; a dialogue with the potential for transformation; incorporation of simplicity, opposition, and reconciliation.	Gadow, 1999.

TENET	DEFINITION	SOURCE
Disease	Energy states with the potential to move one to a higher level of knowing and being; serves as a disruptor to the organizational pattern of the whole.	Newman, 1994, p. 21.
Explicate Order	Outward, transient manifestations of patterns and disruptions; what is mistaken as the "realities" of life.	Bohm, 1980.
Focus of Nursing	"Health as a pattern of the evolving whole…with caring as a moral imperative."	Newman, 1994, p. xix.
Health	Equates to the evolving pattern of the individuals and the environment; evolution of consciousness; Health is disease and non-disease and meaning is found in the evolving patterns.	Newman, 1994.
Hermeneutic	The use of interpretation to search for meaning and to arrive at understanding; interaction of nurse/researcher and patient/subject; knowledge generated from reflection on embedded meanings.	Newman, 2008, p. 9; Gortner, 1993.
Hermeneutic Dialectic	A research methodology involving dialogue on the meaning of patterns of interaction.	Newman, 2008.
Implicate Order	The foundation of the whole upon which patterns arise and flow and have meaning; often subliminal and out of our awareness; the true "realities" of life.	Bohm, 1980.
Knowledge of Praxis	"A thoughtful reflection and action that occurs in synchrony, in the direction of transforming the world."	Newman, 2009, p. 224.
Nurse-Client Relationship	"A rhythmic coming together and moving apart as clients encounter disruption of their organized, predictable state."	Newman, 1999, p. 228
Nursing Praxis	The intersect of theory-research-practice allowing for practice and knowledge development; representative of the dynamic nature of the nurse-client relationship with the inherent possibility to be transformative.	Newman, 2008.
Pattern Recognition	Information of the whole (patterns) are viewed in totality; patterns make individuals unique.	Newman, 1994; 2008.
Presencing	Being one with the patient; engagement; *being with*, not *doing to;* genuine dialogue; potential to transform both patient and nurse.	Newman, 2008.

TENET	DEFINITION	SOURCE
Uncertainty & Disorganization	Periods of crisis or disorganization are viewed as opportunities to transition from one perspective to another, evolving to a higher order.	Prigogine, 1976.
Unitary Transformative Paradigm	A change perspective that human beings are “self-organizing fields” within larger “self-organizing fields” and change is unidirectional and unpredictable allowing for disorganization and re-organization of the whole.	Newman 1994; Newman, Sime, and Corcoran-Perry, 1991.
Unconditional Love	“…being fully present in the transformation of ourselves and others as we allow the meaning of the new reality to unfold.”	Newman, 1994, p. 140.

Notes on Health as Expanding Consciousness

The focus of the discipline of nursing is “caring in the human health experience” (Newman, Sime, and Corcoran-Perry, 1991). In the journey to gain a greater understanding of nursing theory in practice I was introduced to Margaret Newman’s theory of health as expanding consciousness (1979, 1986, 1994, 2008). It is through her work and those nurse researchers who have integrated HEC into their work and into their practice that I came to appreciate this theory as one that gives substantive meaning to my own work. It is a way of thinking that has been with me throughout my career but I never gave it a voice; I never knew it had a name!

The incidence of life-style related illnesses is exploding across cultures, ages, and communities and excessive attempts to control and manipulate the outcomes are failing despite advances in technology and pharmaceuticals. We are unsuccessful in reaching the human heart and soul and effecting change in that critical spiritual domain. The work to be done rests with the need to understand human behavior. “Depression, mental illness, addiction, and obesity point to a culture deeply in search of meaning as old forms and processes fall away" (Koerner, 2007, p. 13). Conventional healing must welcome efforts in spiritual healing, the practice of stepping into the moment, being truly present, and calling into consciousness that which has been out of reach in the subconscious.

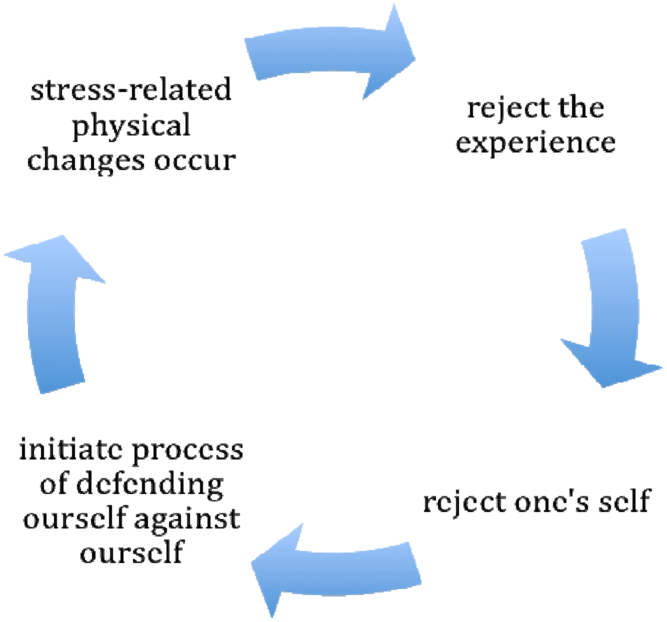
If we think of consciousness as the interactional capacity of a system, we begin to frame experiences in chronic illness as "choice points" in the process of expanding consciousness with response potentials that lead to more meaningful patterns of interaction. Illness is an integral part of wellness, not an opposite end of the continuum from health, as we so often envision. Patients are whole, interactive beings and their experiences have the potential to transform them in their wholeness. Newman describes health as a pattern of the whole, an interaction of person-environment-relationship, of which illness is a part of an evolving pattern. Pharris (2002) describes actions in HEC nursing as those that arise from meaningful dialogue, from being in the relationship and in response to that attentive connection, rather than from a prescribed and pre-determined agenda.

Bentov (1978) beautifully correlates consciousness with the depths of an ocean illustrating the reconciliation and merger of opposites. The ocean may appear tranquil and calm without giving any suggestion of the hidden, unleashed potential energy and creative power harbored underneath the blanket of stillness. This is where absolute consciousness resides (p. 67).

This DNP project interprets the work of HEC research as being in the moment, in the stories, and searching for patterns that emerge as the stories unfold. In the telling of *the most significant events* of one's life, patterns of disruptions and evolution to a higher knowing become evident. This is the search to appreciate expanding consciousness by pulling back the still ocean covering to expose the powerful underlying energy and supporting the creative and energizing potential within.

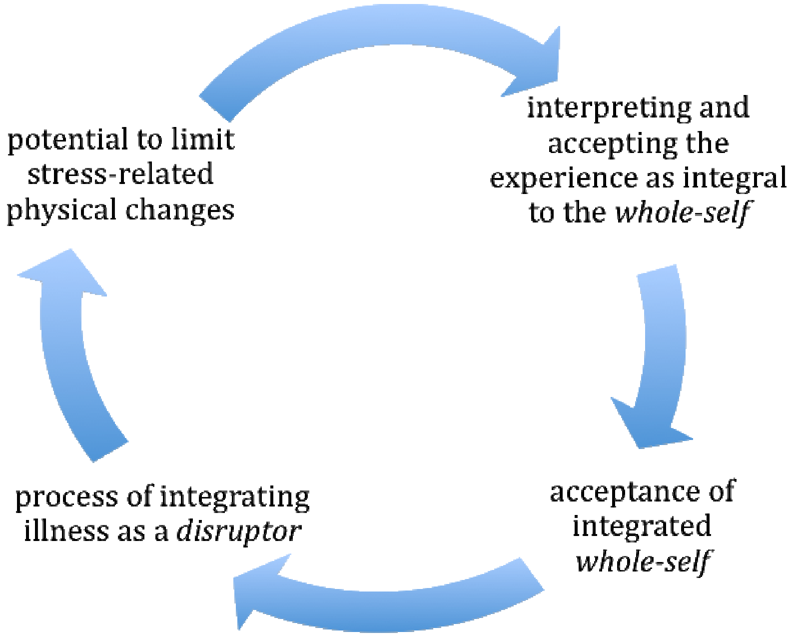
Health as expanding consciousness is the paradigm, intuitive and innovative, that allows nursing to conceptualize disease as energy that has the potential to create movement or disruption leading to a reorganization of the system at an expanding or higher level of knowing. Balance is restored as disease is appreciated, not as an invader or enemy, but as a pattern that unfolds as a reflection of the interaction of person and environment (Newman, 1994).

Discussion is evident regarding the necessity of disease. This incorporates the critical nature of *our response* to disease, which determines how devastating it becomes. The following diagram is an illustration of the destructive cycle that results as a stress response to illness rather than if we would allow for *acceptance* of the illness as a "disruption" (Bentov, 1978; Moss, 1981; Newman, 1994).



Rejection of illness leading to self versus self.

Figure 1. **Stress Cycle of Illness Rejection**



Acceptance of illness leading to acceptance of self as whole.

Figure 2. **Integration Cycle of Illness as Disruption**

Methodology

"Giving up a prescribed agenda…and instead fall[ing] forward to the center of ourselves." (Moss, 1981, p. 39)

The hermeneutic-dialectic approach is a participatory research method where "research takes the form of practice" with dialogue, partnership, pattern recognition, and "health" identified as essential components of praxis (Litchfield, 2005, p. 73). In this project, a series of interviews were conducted reviewing participant life experiences before and after the diagnosis of diabetes. Individual perspectives related to how health care providers did, are, or possibly could "make a difference" in the diabetes experience were solicited. It was assumed that in hearing the previously untold stories of the lived experience of type 2 diabetes, nurses gain greater insights, enabling a more effective partnership with persons affected by type 2 diabetes.

The foundation of the initiative is the dedication to the inherent dignity of the human person, respecting the values and practices of individuals, as well as diverse communities. This encompasses a reverence for the inherent equality of each individual, family, group, or community irrespective of their socio-economic status; a commitment to stewardship; and the promotion of the health, safety, and wellbeing of others to the greatest extent possible.

Study Design and Background

An application for research approval was submitted to the University where the researcher is a student. A second application for research approval was submitted to the University affiliated with a clinic where some participants were recruited and where the researcher became employed. Final approvals from the IRBs were obtained in July 2009.

Three clinic sites were identified as potential recruitment sites for participants. They were selected because they represent demographic diversity but it was clearly understood that this would not guarantee specific diversity representation among the clients who responded to the invitation or who would actually enroll in the study. The researcher contacted providers at each site by phone and received a verbal agreement to offer the study opportunity at their respective sites. The researcher provided copies of study documents to each office for the physician, nurse practitioner, or staff member to review, along with an offer to meet with the researcher for the purpose of reviewing the study. None of the providers accepted this offer but all agreed to participate as a recruitment site. The documents provided included a copy of the study abstract, the patient invitation for study participation (see Appendix A), the participant consent for study involvement (see Appendix B), and the patient questionnaire (see Appendix C).

The providers at the specific sites were asked to identify a staff member who might agree to serve as a contact person for the researcher. This person was identified as the person who the researcher would communicate with regarding invitation distribution, patient inquiries regarding the study, and questions or concerns regarding the study. It was emphasized that the process would require minimal office personnel involvement. At the conclusion of patient recruitment, the researcher contacted the office contact and asked that the invitations for study participation be removed from the office waiting room and discarded.

Researcher contact information was printed on the invitation for study participation and enrollment was conducted independent of the provider office. The goal for study enrollment involvement was eight to twelve participants, two men and two women at a minimum, all over age 18 with a known diagnosis of type 2 diabetes. At a location selected by each individual participant, it was anticipated that two to three interviews of approximately 60-minute duration would be conducted and audiotaped by the researcher over the course of six to eight months. Written consent was obtained before the initial interview. The interview design was to ask three questions:

1. What are the most significant events of your life?
2. Tell me about your most significant experiences with type 2 diabetes.
3. Do you have any ideas or suggestions that you want shared with healthcare providers?

Potential participants were assured that reports of study findings would be stripped of any identifying information ensuring protection of patient, family, and provider confidentiality. Questions and concerns were solicited and addressed by the researcher.

At the conclusion of the initial interview, participants were asked to complete a short questionnaire (see Appendix C) for the purpose of providing the researcher with demographic data and information related to the participant's diabetes history. The nurse researcher engaged in dialogue with the participants as they responded to the questions. Of interest is the fact that questions 1 and 3 were always asked. Information addressing the second question, "Tell me about your most significant experiences with type 2 diabetes," came through in each interview without being specifically solicited.

The researcher reviewed transcriptions of the interviews for the purpose of identifying emerging themes and patterns. Two interview transcriptions were provided to the researcher's advisor early in the study. She diagramed the life events that emerged as she read the interview details, which was helpful in providing insight to the researcher prior to conducting additional interviews. Insights gained were then shared with the individual participant on a subsequent interview for purposes of clarification or validation.

The process of pattern recognition led to important insights. Patient identifiers were stripped from the data, and the project plan was to develop a means to share the insights gained with nurses who have the potential to impact the essentials of diabetes care. *Energy Webs* evolved as a means to depict the patterns identified through interview interpretation. These webs were revised numerous times as a result of participant responses and recommendations. The participants were again assured that "no identifying information would be included in the presentation of study findings." The specific information that would be shared on the individual webs was shown to the participants and changes were made based on participant request to omit or alter any information.

Initially the researcher was not working within an organization. Participants came from two of the three originally identified sites. There was a single patient from one of the original sites and none were recruited from a second. Three months into the study the researcher became employed at the third location, a nurse managed clinic in the central city, which primarily serves patients who reside in the neighborhood. Two of the participants were from this location and were recruited after the researcher became employed; however, they were referred to the study by NPs other than the researcher and strict confidentiality was maintained in accordance with the research protocol. Four participants were referred to the project from a fourth location--a free, nurse practitioner managed clinic. University faculty who also served as providers at the clinic learned of the study and actively recruited patients to participate.

Interviews were generally conducted in the patients' homes, although some of them were also conducted at coffee shops or clinics. Each participant selected the site for the interviews after being given a number of options from which to choose. The nurse researcher and the faculty advisor were the only people to hear or review the transcriptions of the interviews. The equipment used was a MacBook lap top and a digital tape recorder. The nurse researcher completed each transcription as a result of listening to the taped interviews. When the study was designed, 8-12 interviews were planned, however, as insights from the nurse researcher-participant dialogues unfolded, a new method of nursing praxis emerged. The interviews called for further exploration and a need to attend to the process itself. A decision was made to honor the interviews completed and the emergent process rather than to add additional participants to the study.

An Introduction to the Participants

Seven participants with type 2 diabetes were interviewed on at least two occasions, four women and three men. Of the four female participants, one is Caucasian, and three are African American and their ages range from 29 to 64 with an average age of 54 years. Of the three men, one is African American, one is Hispanic, and one is Caucasian and their ages range from 33 to 56, with an average age of 45 years.

Diabetes specific data were collected by a simple questionnaire, which the participants completed prior to their interview. Some of the participants were uncertain of an exact time of their diagnosis of type 2 diabetes, not because of a recall issue, but because all but one participant suspected they had the disease before they were actually diagnosed. The duration of diabetes for the participants ranged from one year to eight years with an average duration for the group of 6.7 years.

Medication regimens varied, with three participants on oral meds only, two participants take oral medication plus insulin; two participants are on insulin only, and one participant does not take medications. Oral medication is recommended but he cannot afford it and indicates he uses lifestyle to try to control his diabetes. None of the participants acknowledged taking “herbal remedies” or supplements for their diabetes.

The ADA current practice guideline recommendations for diabetes specify a target A1C of 7% based on research specific to minimizing complications (ADA. 2010a). When asked about hemoglobin A1C, three participants didn’t know exactly but guessed it was below 7% or in the 7% range. Of the two participants who were confident in knowing their exact A1C, one participant indicated it was 7%, the other was at 15%.

Two participants had no idea what their A1C is and couldn't guess because they didn't remember hearing any number or "percent number."

Home blood glucose monitoring frequency varied among the participants, with two individuals testing "never or less than once a month," four participants testing one to three times daily, and one participant testing one to two times weekly. In addition to diabetes, other illnesses that affect the participants are hypertension (5 participants); hyperlipidemia (6 participants); vitamin D deficiency (4 participants); depression (3 participants listed this as a medical problem but personal experience with depression was discussed by each of the seven participants in the interviews); arthritis (3 participants); chronic pain or back problems (3 participants); and peripheral neuropathy (2 participants). Additional concerns mentioned only once include hypothyroid, asthma, heart problems, sleep apnea, foot problems (not neuropathy), and restless leg syndrome. Although only one participant listed obesity as a medical problem, five of the six other participants are obese.

When asked, "whom do you consider your support?" one participant listed "no one;" three of the female participants listed mom or grandmother—one stating "it used to be my mom before she got Alzheimers." Three of the participants listed the Nurse Practitioners at their clinic and for one of those participants the NPs are the only support. One participant listed spouse and children and one participant listed a daughter. Another participant listed a significant other with a 19 year relationship.

A personal knowing of the *Energy Webs*.

It was through the presencing in interviews that I came to know each participant in ways other than the previous statistics reveal. It is in this knowing that their *Energy*

Webs began to be revealed. Cynthia lives in the central city of Milwaukee and describes herself as not being very social in the neighborhood, and disliking crowds and the kids running wild, the police business, and the fussin' and drinkin'. Hunter came from a big family and knew he would rather be in the north woods with the retriever and his dad and brother on those autumn afternoons than playing high school football. Sam was widowed with four small children when her husband died following a dental procedure and she has been searching for a life to call her own ever since. Big V. describes the overwhelming anger and grief when he came home to find his young wife in bed with another man. There are things in his life he's not proud of but he hopes that his 2-year-old son will teach him to trust again. Woody came from a God-fearing, church going family that never discussed sex and subjected him to verbal abuse. He fell in love at age 13 and fathered his first child when he was 14 years old. After a series of losses including the death of her dog--a trusted companion for eight years, Korky grieved and sunk into depression but distinctly recalls the day she "took a cold shower," and "then a hot shower," and then she told herself "this is it." If LuLu could change anything, she would "maybe change" how she grew up. She wouldn't want her mother in her life. "It's sad to say but it's the truth. It's the truth. I would have a different mother. That's what I would change… *SILENCE…"*

Responding to the Questionnaire

On the study questionnaire participants were asked "What 3 words would you use to describe your experience with diabetes?" The participants responded with the following words or phrases: painful, discouraging, hope, learning, bothersome, unaware, unconcerned, depression, anxiety, awful, contagious, outrageous, shots, meter, angry, hard, stressful, afraid to eat, unwanted sympathy, and makes me a part of the family. The same response did not appear twice.

When asked to include anything on the questionnaire that the participant wanted the researcher to know, the responses included a plea to listen to the patients; be truthful; keep the teaching programs simple but honest; tell it like it is; realize that depression cycles with diabetes; keep the teaching basic and provide down-to-earth medicine; treat patients with mutual respect ("my NP treats me like an equal, we have a partnership"); and realize that "I may be old, fat, and diabetic but I am not stupid!"

Emergent Methods

At the heart of each of us, whatever our imperfections, there exists a silent pulse of perfect rhythm, a complex of waveforms and resonances, which is absolutely individual and unique, and yet which connects us to everything in the universe.

(Leonard, 1978, p. xii)

The Concept of Energy

Einstein's theory informs us that all matter is energy and therefore all beings are considered *dynamic systems of energy* (Koerner, 2007). This perspective describes the human being in:

> …dynamic exchange with complex and diverse regulatory energetic fields….health and healing includes influencing the subtle energy fields surrounding the body instead of simply manipulating the cells and organs with drugs and surgery…we are powerful creators of our lives and the world in which we live. (Koerner, 2007, p. 65)

It is in the interpersonal connections and the energy within that healing relationships and movement toward wholeness are fostered. Koerner (2007) refers to each soul as having its own pattern of energy on the path to becoming that which it *holds within itself (p.135).* The intersect where nurses meet patients is where movement creates rhythm against the landscape of diabetes. It is this environment of energy flow of souls that is life giving and allows for the possibilities of genuine diabetes care engagement.

The Spin on the *Energy Web*

A hands-on model began to take shape late in the project as interpretations of participant interviews, pattern recognition, and written summaries failed to capture the essence of the experiences. Initially diagrams that were designed by the researcher were based on HEC diagramming as found in the literature (Capasso, 2009, p. 68) were less than optimal when shared with participants. It was the search for more—the experience of a best plan "not working"—that led to the initial trial of the *Energy Web.* Each Web became a pictorial representation of choice points, connections, personal development and hierarchy of needs, diabetes specific aspects of care, aspects of social justice, life's anchors, and individual values that reveal the intricacies of the "whole" of each person in their experience with type 2 diabetes.

Energy Webs reflect the movement of energy and dynamic relationships woven from individuals-environment-communities, creating a "wholeness" to be appreciated. A tug, a breeze, a disruption in one corner of the web affects all parts. The web may appear disrupted, analogous to the explicate order as described by Bohm (1980). The chaos is manifested temporarily, visibly, yet what is critical is that the web remains essentially whole because of implicit order, or the foundation upon which the web is built, the anchors that secure it. It is an appreciation of the implicit order of life and wellness/illness that escapes the practice of medicine. It is the implicit order that gives meaning to the *Energy Webs* and it is in the implicit order where nursing dwells. The *Energy Webs* are an exquisite expression of moving from medical-model ideals of health toward "embracing a unitary pattern of changing relationships" (Newman, 1994, p. 13).

The web analogy here is simple in theory yet beautifully intricate when played out in the lives of those with type 2 diabetes. Webs are secured at points for durability and security. People do not exist in isolation and their webs are also grounded. Through interviews and work with pattern recognition, the anchors in life are identified as: Basic Needs, Contributions (Purposefulness), Participation (Support and Connectivity), and World View (Beliefs and Perspectives) (see Appendix D). These anchors evolved from patterns that emerged during the process of returning to the interview transcripts again and again, and then taking the ideas to participants for their perceptions and input.

Catholic social teaching identifies the tenets of social justice, which are also an integral part of our work as nurses and reflected in the *Code of Ethics for Nurses with Interpretive Statements* (American Nurses Association, 2001). Nursing for social justice is built on twelve principles that are integral to the promotion of human dignity (Kalb, 2009). The principles are: human equality, rights and responsibilities, call to family, community and participation, dignity of work and rights of workers, option for the poor and vulnerable, solidarity, subsidiarity, common good, stewardship, economic initiative, and charity and justice. It was in returning to the transcribed interviews and the stories participants told that the principles appeared integral to the *Energy Web* and concordant with the identified anchors (see Appendix E). This maintains the call to nursing to be mindful of the tenets of social justice in daily practice as individuals and as a discipline, and to reflect on underlying virtues that were described in participant stories.

The spindles of the *Energy Web* represent two concepts. The first is that of Abraham Maslow's hierarchy of needs described in the 1940s and addressing human development theory and concepts of human motivation. The second concept addresses the need for blood glucose control for minimization of complications. The object of diabetes care engagement is partnering with patients in the effort to fit the disease into the individual's life, not to have the individual adhere to impossible or meaningless medical regimens. The participants suggested key ingredients and effective strategies in the newer paradigm of diabetes care engagement. The work of diabetes care engagement takes its proper place on the spindles that coordinate with web anchors, alongside the developmental spindles.

In the *Energy Web* the structure of Maslow's needs is not hierarchical as his work demonstrates but rather it is presented as parallel, coordinating spindles, each continuing to grow, advance, and become more useful along with life experiences. The suggestion here is that at any point there may be a threat to one spindle, but work accomplished at other spindles maintains web connectivity and a means for growth, expansion, and web repair. Just as the spindles are the means of safe and efficient movement for the spider, the acquisition of the tools for diabetes self-care, or lack of these tools for any reason, translate to disruptors, either treasures or trappings, in the *Energy Web.* For example, participants described the devastating impact resulting from a lack of diabetes education, or the insecurity and self-doubt that evolved because they were unable to self-inject insulin. Participants described being listened to, being involved in decisions about their diabetes plan, and achieving personal goals for controlling their diabetes are suggestions of treasures. The work of diabetes affects the whole spiritual, physical, emotional, and psychological person and the work of diabetes is energy in the movement of expanding consciousness.

The concentric woven circles or rings are symbols of life experience. The web growth is dependent on *disruptors* that call the web-dweller to attend, assimilate or reconcile, and move on. Each level or woven ring represents transformation, an *all at once* movement described as *the most significant events* by participants. These events are truly the *disruptors* and identified by the participant or *web-dweller* as *ttappings* or *treasures.* These *disruptors* are the *choice points* in life. The connectivity of the silk weave illustrates that any disruption in one area of the web will impact the entire web just as one's response to any choice point will impact life's *Energy Web.*

No two webs are the same and no two webs are secured tightly at all points at all times. It is interesting to contemplate what happens when a disruptor tears the web from one of the anchors or leaves a gaping hole in a specific quadrant of the web. This is exactly the inquiry that needs to be made by each nurse as we journey with patients in their experience with type 2 diabetes. What is the web that each individual web-dweller has spun? What is the experience with disruptors and how are they labeled? What is the web integrity? Where is the strength and weakness in each individual web? What are the anchors, the virtues, the level of needs met or unmet? How expansive is each web and is that representative of their perception of "health"? What is my own web and how does it influence the lens through which I view another's web? Therapeutic presencing, honest dialogue, and thoughtful caring will help secure the moral compass to guide nurses as they seek insight and understanding.

Energy Webs are the visual representation of themes of complexity and connectedness that emerged from dialogues with participants. Although the basic web "model" was a simple concept initially, once designed and incorporated into the interviews as a means for validating pattern recognition, it evolved dramatically and with ease, and clearly resonated with participant and nurse researcher alike. It allowed for integration of HEC from the researcher perspective; it facilitated a reinterpretation of the stories depicting the most significant events of participant's lives; and ultimately it allows for greater understanding of diabetes not as disease but as life-long encounters with "choice points" and one that nursing is privileged to be an active participant in.

Analysis

Web Basics

> *"When we begin to think of ourselves as centers of consciousness (patterns of energy) within an overall pattern of expanding consciousness, we can begin to see that what we sense of our lives is part of a much larger whole."* (Newman, 1994, p. 24)

As the research unfolded and participants shared their lives, the model of a *web* came into play as a means to capture the dynamic nature of expanding consciousness. A search of the Internet offers a glimpse into the science of spiders and their daily work of web-spinning. It leaves one with a new-found appreciation for spider webs as intriguing pieces of creativity and ingenuity in nature that are amazingly purposeful, dynamic transmitters of energy. Spiders' bodies produce the webs from protein-based silk. Initially this was used for protection and later evolved as a means of quiet communication, efficient mobility, and of securing nourishment.

Spiders move cautiously up and down the web spindles taking care not to become trapped in threads of their own. The more movement, the more work, and the larger the web, the more developed the spindles become. Movement of the threads transmits energy and signals the presence of a disruptor to the woven masterpiece, which may be as innocent as a gentle breeze or as threatening as a harmful predator. It is the spider that has the innate sense to identify the disruptor as a treasure, the next meal, or as a destroyer, something threatening harm to the spider or the web integrity.

The spider web has a stronghold in Native American culture and traditions. The dream catcher, when placed over sleeping babies, will allow good dreams to pass through the hole in the center of the web but the bad dreams or evil spirits become trapped in the webbing and rest as glistening droplets on the threads until the morning light abolishes them. (Native American Technology and Art, 2010). It is also said that the hole in the center of the web is representative of the emptiness inside ourselves but it is the sacred place that gives us the space to create. *Spiderwoman,* with a rich tradition in Native American culture, is said to spin her webs from this center of emptiness. The legend of *Spiderwoman*, as retold by Koerner and Bunkers (1994) speaks of her power in rescuing the Navajo people from a flood by weaving a web on the water's surface to keep them safe. The Native American legend also credits *Spiderwoman* with teaching the Navajo ways of thinking by creating web designs. There is a wealth of creative possibilities in the concept of the web.

The “healing web” is described from a social science perspective by Pilisuk and Parks (1985) in the study of human connectedness, social support, and the true nature of caring. Evidence connecting breakdown in long-term relationships within families and communities to isolation and contributing to disruptions in health is discussed. It is the nurturing and life-sustaining qualities of human interdependence that contribute to individual and community physical and emotional well-being and without the connections society as a whole is at risk.

Koerner and Bunkers (1994) use the “healing web” as a model enhanced by a work group of nurses that symbolizes the “true integration of nursing education and nursing service into a synergistic whole” (Koerner & Bunkers, 1994, p. 53). The core concepts described are authenticity, caring, and interdependence, which are integral to the web model and deeply influential in addressing the caring dialogues and ways of being in communities of nursing. Health as expanding consciousness is the foundation of the conceptual framework and the work outlines the underlying philosophy as well as the “caring capacities of the nurse” (p. 55).

Koerner (2007) addresses concepts integral to the *essence of nursing* moving to the center of *doing* and *being* as the two dimensions of nurse work. The choice points she refers to are the decisions that we make that get us *stuck* in our webs or allow for expansion of them. The concept of the healing web speaks to the expanding, transformational nature of knowledge, dialogue, and partnerships. From this work numerous themes are identified that contribute to the advocacy of a “healing consciousness” suggesting potential healthcare transformation that begins within the community of nurses. Dialogue in the *Energy Web* is similar to themes identified in the

Healing Web, illuminating the importance of being genuinely present as a means to truly hear and understand, allowing for the generation of insight and creative thinking.

Discoveries: Patterns that Anchor the Stories

Webs gain strength from having solid and secure anchors and if one anchor is weakened, the web draws strength from the contribution of the other anchors and the web-dweller works to repair the fractured connections. Dialogue with the participants and review of the interviews clearly identified what anchors individuals in their webs.

"Basic Needs" is identified as the first of four anchors and it evolves as one aspect of the lives of the participants reflecting the importance of physiologic balance, safety, and security. The coordinating tenets of social justice in this realm include a preferential option for the poor and vulnerable; as well as a commitment to the common good, which involves the assurance of human dignity and conditions that allow for the full expression of human potential, as well as stewardship of resources and protection of the earth (Kalb, 2009). "Effective diabetes education" is the diabetes specific work in this anchored area and it is connected to efforts to ensure that basic needs are met.

Table 2 reflects the organization and components of the *Energy Web* including the four anchors, associated hierarchy of needs, the work of diabetes, and the complementary tenets of social justice.

Table 2
Energy Web Quadrants and Associated Tenets

ANCHOR#1: Basic Needs Complementary Social Justice Tenets -Option for the poor and vulnerable -Common Good -Stewardship Hierarchy of Needs -Physiologic -Safety & Security	ANCHOR #2: Connections and Support Complementary Social Justice Tenets -Call to Family -Call to Community & Participation -Solidarity Hierarchy of Needs -Love & Belonging Work of Diabetes

Work of Diabetes -Diabetes Education	-Diabetes Self-Care
ANCHOR #3: Contributions Complementary Social Justice Tenets -Dignity of Work/Rights of Workers -Subsidiarity -Economic Initiative Hierarchy of Needs -Self Esteem Work of Diabetes -Skill Mastery	ANCHOR #4: World View Complementary Social Justice Tenets -Human Equality -Rights and Responsibilities -Charity and Justice Hierarchy of Needs -Self Actualization Work of Diabetes -Humor & Optimism

When a basic sense of well-being is threatened, stress may ripple throughout other aspects of the web. The "disruptor," whether perceived as either threat or treasure, stimulates the process of expanding consciousness. A few stories, often reflecting values of respect, self-discipline, and integrity that correlate with "basic needs" are as follows:

LuLu told this story*: I didn't really …I mean when I was pregnant I don't remember getting any type of pamphlets or anything like that. So it was, you know, I just thought it was something that came with every pregnancy. I found out I was diabetic, I just kept getting really really sick…I was calling into work; constantly going to the bathroom. I was sleeping with gallons of water at my bedside. I kept going to the emergency room and no one knew what was wrong with me. This was after my miscarriage…that's when I was thinking "Oh my God- I'm pregnant again…I am gonna go through this again…" I was like "I am sick all the time… I can't sleep for going to the bathroom at night…every other hour." And the doctor said "have you ever been tested for diabetes?" and I said "not that I know of". So she started asking me family history and I explained that my father passed away in the year 2000 he was only 34…and people on my mother's side had diabetes and passed away from complications of diabetes. She said I really would like to do a blood test to see if you're a diabetic. And it* *came back and she said yes; the numbers were really really high. And we just took it one step at a time.*

Woody described his health at the age of 34 *I have high blood pressure. I have sleep apnea and I'm getting worse. My diabetes is worse; I have the nerve problem-diabetes…neuropathy. I have to see a sleep specialist for apnea… and I have restless legs… I have chronic back pain and that's not gonna go away but hey, I take my meds and what else can I do? I have depression and it hits real bad every three months. It's a cycle and if I'd get a job every three months it would creep up on me and it's real bad. I don't know how I know this stuff…I just notice this. I spend a lot of time thinking, meditating, reading the Bible…I notice these things…these things are based on emotion…*

Sam knew she was ill and struggled to understand what was wrong, stating, *I really felt crummy, extremely crummy. I'm not sleeping, probably cuz I'm getting up half a dozen times a night to pee because I've always been a good water drinker. Now here's the point of this. They give you all the symptoms of diabetes it's not like one day your pancreas stops, like, one day your fine and the next you're not. It's not sudden symptoms. It's a very gradual thing. So, anyway, I remember being in the airport in Atlanta…it's a very immense airport. Well of course I have to transfer from one end of the airport to the other…I remember trying to get through the airport, almost passing out, because I just felt so rotten. Gulping water like crazy. My throat felt like, when you're thirsty and you're diabetic, it literally feels like your throat is gummed shut. The most thirsty you've ever been and you can't do anything. Well I'm drinking my water bottle; I get on a train* *going the wrong way, nearly missed my flight. Came up here for about three weeks for my dad's funeral…the stress is doing a number on me.*

Cynthia "*knew something was wrong but I didn't know what it was..." "…I kept asking them to test for diabetes...I knew I was gonna get it…it was in my family…I guess it's cuz I didn't have the insurance…"* Cynthia talks about primary care at a nurse practitioner free clinic: *"It was a blessing I got to the free clinic, they found my diabetes…I like the doctors there. They explain things, I ask questions and they answer them for you. Like when she gave me my pills she told me what this is, what it is for…what symptoms I might have…they talk to you. They don't just examine you and just push you out, they talk to you..."*

A second pattern that emerges from the stories is that of the significance of "Connections and Social Support" and those lives that long for this support. A call to family; call to community and participation; and solidarity, which addresses all individuals as part of the greater "human family," are the tenets of social justice (Kalb, 2009) and are evident in this quadrant of the *Energy Web*. In this area, love and belonging and diabetes self-care are consistent areas of growth and connections in this anchor quadrant and complimented by virtues including balance, tenacity, and intuition.

Cynthia worked as a nursing assistant and talked about why she chose home care. *"Sitting down, talking to them…walkin' them to the parks and stuff. And then they have me like family and they come over on holidays…The company called them and told them I wouldn't be back. I still have one client, she would call me anyway… she liked for me to fix her eggs and she'd call…Cynthia, Cynthia, please come over and fix my eggs. I* *folded mine, they scrambled 'em and she didn't like the little knots in them like that. It was hard when I couldn't go back…sometimes I would go back and just talk to them."* Woody: *"…There was verbal abuse in my family towards me. I was the black sheep. I was punished. I saw her every day. She would do the craziest stuff…she wasn't retarded or nothing…She was sick in some way. Other mothers would come to the school she would stay behind. I had to grow up with that and I took the verbal abuse like this is the way it is…"*

LuLu, age 29, had a life of abandonment and loss. She struggled to find security in her childhood. She describes a portion of her childhood as follows*; everyone was telling me I was too young. I wanted to take care of my brother and sister…Even when I'd call my grandmother and say can you come get us I don't know where my mother is she's been gone for several days. I was 9 or 10 taking care of my brother and sister. I would always give my mother a day or two before I would call my grandmother because I knew how to clean and I could cook- simple things as far as food. I knew how to take care of my brother- he was still in diapers. I was nine, my sister was probably five, and my brother was two. I would give it a day or two…I wouldn't go to school the next day because who would take care of the other two if I went to school? So after a few days I would call my grandmother and say, "I don't know where our mamma went. She's not here." And she would say, "oh your mamma just this that or the other thing. She's just a little sick." That's all they ever said, "she's just a little sick." So when I got older, I asked, "Does she do drugs? Does she drink?" "What? No your mom- she's just not right." So I grew up just thinking she was crazy. But they would come get us, the people on my father's side…*

Sam left home at age 16 and the next years included three marriages, death of her first husband, and numerous relocations in four states. "*…My parents never accepted me for me- not personality, not physically. My father was probably schizophrenic from what we can figure out. My mother is probably bipolar. They were both alcoholics so I didn't quite fit into their little mold of what I was supposed to be…"*

Big V. discussed the fractures in his connections and social support in his childhood: "*…Raised in Milwaukee with a broken family. I used to hate to hear...It's not a jealous thing…other kids say 'mom's cooking' for the holidays… cuz I was with my father…he lived with his mother, his sister and I feel like she never really wanted us there. She would always make little comments like, 'your father needs to get his own place'…When I got old enough…big enough…when you hate to go home it's a hurtin' thing…not like you were missing no meals or nothing like that…I wasn't happy with the way I was living…and always trying to make someone happy when you aren't happy yourself…when you can learn to love you you'll be alright. Always looking out for the next person who doesn't give a rat's ass about you…and I felt that way…"*

A third pattern that is integral to the *Energy Web* is that of "Contributions." The social justice principles include the dignity of work and rights of workers; subsidiarity which may be described as the freedom of initiative to be included in government/medical decisions; and economic initiative, or the right to use one's gifts to contribute to the good of society (Kalb, 2009). Self-esteem is an inherent need addressed here and skill mastery is the diabetes care work that is described in the interviews. Virtues eluded to by participants include integrity, personal validation, and sense of purpose. These are stories of energy investments and imbalances, allegiance to work and job loss, as well as care-taking of family or friends, often at very young ages or when the participants themselves had very little energy reserve.

When asked about the most significant events of her life, Korky responded immediately as follows: *"…When I was able to work. Working…because I had a job at a small group home that I was in charge of…but I really got a chance to know a lot of the residents and their families and I had a big part in the Alzheimer's program and I understood it very well because I had two aunts, one that has Alzheimer's now and one that passed away with Alzheimer's and I go and see her so that was the thing…it just seems that when you stop working seems like your life just shuts down almost…"*

LuLu's story also described loss of the ability to contribute. *"…She put me on…I think it was Avandia and Amaryl and it worked for a little bit. Then I ended up losing my insurance through my job cause I lost my job cause I missed too many days of work due to the complications of diabetes but I didn't know…and so I end up losing insurance and therefore I couldn't get the medication she prescribed for me and I ended up trying to get assistance from the state and they switched the medication. I have had complications ever since…"*

Big V offered this: "I wasn't eating right…I wasn't sleeping right…I was rippin' and running and doing whatever I felt… wasn't attached to no one…I wasn't living right… and then I laid on my bed and cried and I just wanted to give up."

Hunter was challenged between his work as a carpenter and his work as a foreman. *After that job was finished I called the guy up, the guy who managed the manpower for the first company and he said, "no, we don't have any work," so I just kept working contract to contract. Didn't realize for a while…I got a call from the guy who* *managed the yard for that company and he said you had to turn in all your tools for the company. I asked why-I'm trying to come back…then I called the guy and he said "it's all water over the dam." He wouldn't give me a reason. I just got slid out the door. I don't know what I did or how I did it and it took many, many years to figure it out. It's your life…your identity… It wasn't until many years later that I saw some of this happening to other guys. They got hurt, they come back to work and all of a sudden, they're gone. I heard someone say they are a liability to the company. They tapped into the workman's comp and they don't want you out there. Too much legal stuff if they don't take you back, so, you go back and all of a sudden they don't have any work for you."*

A final anchor reflects the "World View" of each participant and how that influences their *Energy Web* and whether they perceive disruptors to be treasures or trappings. Human equality, rights and responsibilities, and charity and justice describe the social justice principles specific to this area (Kalb, 2009). Self-actualization is the developmental work and participants recommend humor and optimism as important components of diabetes care. These stories reflect virtues of resilience, faith, and ethical concordance that mirrored despair, hopelessness, depression and "not being heard."

Hunter experienced a number of work related injuries that resulted in disabling chronic pain issues. He researched Prolotherapy, a nonsurgical procedure for reconstruction of ligaments. The procedure involves injecting a dextrose solution into the attachment of ligament or tendon to bone resulting in a localized inflammation. The increased blood supply stimulates tissue repair. This is not a conventional treatment but one that Hunter was interested in. He stated: *"…I have a lot of animosity toward insurance companies and doctors. In spite of the fact that my dad was a doctor, he was a* *prominent surgeon… Conventional medicine let me down. I don't think it's necessarily the doctors although I was really disappointed in my surgeon when he said you shouldn't have surgery but he gave me nothing else to go on- no, here's what we can do. In the back of my mind some day I'm gonna write him a letter. I know he gets the reports from the other doctors but I will write and tell him, here's the result of your decision. When I asked about Prolotherapy- you didn't jump on it, even though there were no side effects. I had nothing to lose. Had you done that, financially I would have been much better. Financially- we almost lost our house, and we were facing bankruptcy. You're not only dealing with my back, you're dealing with my whole life and you gave me nothing to go on.* ***.*** *There was no alternative…"*

Woody described adolescence in the following way: *"…I dropped out at the 10th grade level and she dropped out at the 10th grade level also. We didn't have nobody to watch our kids so we could go to school- so…we've been on our own since. And we just stuck together like glue. A lot of people didn't like that. They didn't like the fact that we were gonna stay together. We went back and got our GEDs…I got mine in 2008, and she got hers and now we go to MATC. So that's why I say, it turns out for the good. It depends on how you handle it you know. You can have an excuse for everything. I can't do this... you're gonna lose! We tell our kids to stay in school because they saw us …."*

Big V reviewed his experiences: *"…It hasn't all been good. But it seems like when you put your trust in someone those are the ones that hurt you the most.. So no I don't trust people and that's why I don't have a wife. I like a woman…I don't love. I want to be loved…I want to be able to reach and touch and feel….the love, the warmth, the caring… so no I don't have love for people like I should. I've been like that for a long* *time…just numb to certain things…”* Big V. paused, offered an apology that he is “not a singer,” and in a sweet, gentle voice he began to sing in a melody reminiscent of an old southern hymn: *I am walking in darkness but I can see the light.*

Sam shared her story in a pressured manner:*…So, finally, I am reaching a breaking point. I’m trying to give you a condensed version of my life. It does no good to be depressed cuz it just makes you feel crappy. Somehow in a bad situation, some good comes from it eventually. So who knows? Maybe me being diabetic, I’ve met you, you write a book and maybe that saves someone’s life someday. In some bizarre way it works…”*

“In 2002 I was depressed, and now, I have hope. For a moment it sucks but then it gets turned around for the better. That’s how I generally look at this disease…my mother was a diabetic and so was my brother. She was diabetic, she had problems.”

Recognizing the Energy Flow: Validating the Patterns

According to Young (1976), pattern is an interconnection of rhythm, movement and diversity with a constant flow and exchange of energy. Our life patterns are significant in that they identify us and are uniquely our own.

It was a common response for participants to minimize their investment in others throughout their lives. *Energy giving* choice points, or treasures, color-coded green on the web and *energy depleting* events, or trappingss, color-coded pink gave participants a visual review of the energy flowing out compared with that flowing in. It was curious that in considering the predominance of pink, or *energy depleting* events on some individual webs, participants were somewhat reluctant to acknowledge the fatigue, energy drain, or “complete and total giving” of themselves with little reciprocal support. Korky pointed out "*Well, I didn't do all that much…*" and LuLu responded, *"It wasn't that difficult because you just do what you know you need to do…you don't think about it."*

This was part of Korky's story for many years when she tried daily to meet the demands of her nursing assistant job, not disclosing to anyone that she was in chronic, nearly disabling pain. This was compounded with demands of caretaking for her ex-husband who was dying of cancer; caring for her ex-husband's father who died at age 102 and then cleaning out his apartment following his death; traveling out of state weekly to tend to her mom who was diagnosed with cancer; and offering support, education, and physical care to an aunt with Alzheimer's disease and her family. When we could together consider the associated fatigue, physical illness, or depression that surrounds those choice points, it was then that the participants acknowledged it to be a *rough time in life* or *something I just was never aware of.*

Energy Balance and Choice Points

The concept of energy is one that emerged in this project as each participant highlighted events in their lives when they were physically, emotionally, and/or psychologically fatigued and felt that their energy was dwindling. One participant stated it was as though "*without noticing a thief came into my life and robbed me of all my energy…I just couldn't do it anymore…I was exhausted…"*. Diabetes itself is a disease that places people at risk when excess glucose, or energy, accumulates in the bloodstream but this vital nourishment is unavailable to the cells because of insulin deficiency or resistance.

The level of investment each participant had in *taking care of others* escaped their awareness initially. Participants began to realize their personal imbalance of energy using the "Web" as a visual illustration that the energy they expended, especially in *taking care of others,* far exceeded the energy generating life experiences. Often this energy depletion correlated with times described as being *out of control* with respect to their diabetes. Physiologically the body had energy available yet because the participants lacked access to tools or strategies to utilize the glucose, the resulting excess energy became detrimental. Using the analogy of the dynamic nature of energy, participants began to understand that movement at any time, in any facet of the web, would impact many other aspects of the woven connections. This opened to new possibilities for participants to put their past in perspective and to look toward the future. See Appendix F for a sample *Energy Web* of a participant with energy depleting experiences plotted on the web in red and energy generating experiences plotted in green. These are the *choice points, trappings or treasures,* of expanding consciousness contributing to the unitary transformative paradigm where change is unidirectional and unpredictable allowing for disorganization and re-organization of the whole.

Recognizing the Energy of Virtues

Virtues are qualities or traits that serve as the foundation of pattern recognition. They appear on the perimeter of the web and although aligned in specific quadrants they influence all aspects of the web, including the energy flow. A search for or commitment to a specific virtue helps in the corresponding areas of personal development and diabetes care. It also appears that the stronger the foundation in the specific anchors, the stronger the coordinating virtues. The virtues listed were pulled from the interviews although this is not an exhaustive list (see Table 3). Additional interviews may likely add other virtues.

Table 3
Integrated Virtues

1. Honesty/truthfulness
2. Ethical Concordance
3. Humor
4. Balance
5. Resiliency
6. Tenacity
7. Integrity
8. Respect
9. Sense of purpose
10. Personal Validation
11. Intuition
12. Self-Discipline

The Ebb and Flow of Energy: Patient and Provider

The participants wanted to be certain that their messages to healthcare professionals were delivered. Sam spoke directly to the question of what healthcare professionals might do differently in the diabetes experience. *"This thought came to me: 'work with me, not against me.' There is more to me than my diabetes. My identity is not 'Sam the diabetic.' I am a person with all these different interests. I have been labeled diabetic so all of a sudden…that is who I am to these people. I am a food addict...I am either a good girl or a bad girl…I am either a good diabetic or a bad diabetic…I do what I should or I cheat on my diet. This is a total upheaval. I am being talked down to. I feel like I am an adult, an intelligent person, treat me like that. I don't know if it's because I am now Sam the diabetic and now I have a lower IQ."*

Big V reflected on his experience. *"Sometimes we need to be encouraged…we get down on ourselves when you have diabetes, I cursed the lord…you give me both blood pressure and diabetes…you couldn't give the diabetes to someone else?"*

Woody was passionate when he asked that doctors and nurses understand. *"When I first got diagnosed with diabetes, I was mad. I said 'forget everything.' Once you get diagnosed, you're upset, you're mad. The first thing any human being does when if you don't know you're scared- you rebel. You don't know anything. So I said no to* *treatments…I would like you to talk to people with diabetes; warn them; teach them;…sit 'em down and let 'em know the whole truth…give 'em options… no scare tactics……are you scared? Do you have someone that can help you with this? Give 'em options…warn them…this is a progressive disease. Teach them everything… ask 'em about depression…how are you doing? This disease is about emotions. There's so much that goes on. Show 'em total respect. Say hey, I understand… if you can't do this…can you do this? Let's start somewhere. Show 'em, explain it…I know it's a lot for a diabetic but there's always something we can do – no matter how minimal. You gotta start somewhere."*

The pleas were sincere and direct. There was not a dialogue opportunity that didn't involve the participant expressing sadness or anger over not being listened to, not being helped, or not being understood by those healthcare professionals who should have been making a difference for them in the experience of diabetes. Most participants accepted ownership for their role in poor health or lack of blood sugar control. In discussing concerns about the educators or providers, they were clear that "it wasn't all their fault" and each owned responsibility for not "following doctor's orders" at some time, in some way. The descriptions of the patient/provider relationships resonated as energy depleting in general. There were descriptions of "fighting to be heard,""trying so hard to get someone to understand', and "it didn't matter how much I accomplished, it was never good enough." It was clear that, in addition to hyperglycemia, the energy drain of relationships with healthcare providers was contributing to fatigue experienced by the participants.

Participants also emphasized favorable experiences when their primary care providers were nurse practitioners. They describe these relationships as partnerships where their opinions are respected and they are helped to understand what is going on with their bodies. Clear, honest communication was the treasure. One participant appreciated the nurse practitioner but did not feel respected by the educator and other staff members.

Societal Energy Exchange: Return On Investment Dilemma

Current diabetes management strategies are costly; energy investment to effect behavioral change is exhausting; and the overall results of these strategies demonstrate minimal effectiveness. The return on investment (ROI) for this DNP change project is evaluated in terms of the intangible benefit with the understanding that eventually the intangibles may positively impact the tangible goods exchanged. The interests of the stakeholders, specifically the patients and families affected by diabetes, and health care providers—including physicians, nurse practitioners, and diabetes educators--are taken into consideration. Differentiating burden of diabetes care versus burden of diabetes (Hirsch, 2003) is an attempt to illuminate the financial drain on an already challenged healthcare system, as well as the complexities that patients experience in their attempts to manage this “chronic and progressive” disease.

Results of the Diabetes Prevention Program (DPP) study demonstrated that prevention or delay of type 2 diabetes may be accomplished by achieving a 5-7% weight loss, eating a healthy diet that is rich in fruits and vegetables, low in fat and calories, and increasing activity to an average of 30 minutes five days weekly (Diabetes Prevention Program Research Group, 2002). Participants considered high risk for development of type 2 diabetes, who engaged in the arm of the study that incorporated "lifestyle modification," reduced their risk of developing the disease by 58 percent. Through diet and exercise they lost 5 to 7 percent of their body weight (Diabetes Prevention Program Research Group, 2002; U.S. Department of Health and Human Services, 2009). The focus of diabetes care is on this well documented research regarding the powerful benefits of lifestyle changes, yet for the underserved and marginalized in our communities the dilemma is beyond the widely held assumption that some people simply won't commit to making these changes.

Diabetes is taking its toll in lives, limbs, and dollars and may be oppressive to the human spirit. Frequently researched variables influencing effective diabetes management include limited reimbursement for diabetes management and education, the current certification process for American Diabetes Association recognized education sites, trends in the pharmaceutical industry, anticipated health care reform in light of the current economic climate, and the financial burden of self-care. The deafening silence is from the absence of patient voices sharing insight into their experience with diabetes care. *Energy Webs* give their stories a voice.

Spinning the Webs

"*To be open is to be vulnerable…The need is to let go, embrace our experience, and allow the expansion of consciousness to unfold*" (Newman, 1994, p. 142)

The outcomes of the "*Energy Webs* and Praxis" simply *are what they are* and that is the gift. Early work on this project led to uncertainty regarding qualitative research data collection and analysis of data. There was concern as to where the interviews were leading and what they meant to the participants. Perhaps there would be "nothing" as a result of the interviews that would suggest a formidable change in nursing practice or diabetes care. The project began as a passionate but somewhat amorphous endeavor that began to take exquisite shape as the voices entered. The objective was not necessarily to find common threads among the seven participants, but rather to uncover individual patterns and consider how these patterns impact diabetes care engagement in the past and for the future, In those patterns would be insight into the individuals in front of us, who guide us in our interventions or "non-interventions." A glimpse into the participants' choice points may offer possible connections to their individual experiences of type 2 diabetes. Any findings that inform nursing practice and positively influence the experience of type 2 diabetes for our patients would be a valuable move toward change.

Participants appreciated the opportunities to tell their stories, recalling significant events in their lives, considering their diabetes specific issues and disclosing them honestly, without fear of judgment. The work of pattern recognition leading to a review of choice points was a different experience for each individual participant. In reviewing the individual's *Energy Web* with them, "That's it…how did you know that?" was not an uncommon reaction. Of course, this was simply information they had shared in discussing their most significant life events. "When I look at this, I think, it's by the grace of God that I am where I am today, isn't it?"

For the nurse researcher there is the gift of praxis that translates to connecting, presencing, and working with the participants in the process of pattern recognition and in appreciating individuals as *undivided, whole beings, body, soul, and spirit.* "Caring as a moral imperative" (Newman, 1994, p. 140) transcends ministering to physiologic needs and ministers to the soul as well. "Care of the soul…isn't about curing, fixing…or making healthy...it remains patiently in the present, close to life as it presents itself day by day…" (Moore, 1992, p. XV). This is the responsibility for nursing in the new paradigm that the profession is called to embrace.

It is a humbling opportunity to "fall forward" into the participant experiences as they unfolded (Moss, 1981, p. 39). It is a balancing act in our daily work and we are called to be mindful of our own individual webs and how we can allow them to mesh with the webs of those we serve. We strive to focus on patient and family needs; to respect our dedicated colleagues in the healthcare profession and in diabetes education; to recognize the contributions of the ADA curriculum and the well-developed, evidence based, self-management programs; and at the same time to seize opportunities to re-consider, re-envision, re-energize, and re-invent our collective webs in the world of diabetes.

Discussion on Future Web Spinning

"Nursing's task is not to change another person's pattern, but to recognize it as information that depicts the whole and relate to it as it unfolds." (Newman, 1994, p. 13)

A number of next steps emerge as a result of "*Energy Webs* and Praxis." At the most basic level is the call for nursing praxis in diabetes care. Returning to our traditions in nursing with caring as the moral imperative and embracing this as a way of being in our practice is critical as we look to effect change. The integration of health as expanding consciousness allows us to make sense of our world, of our experience with illness as one in being with wellness, and to continue to appreciate our connections with our communities, our environment, and ourselves. This process of engagement in the life stories led to a partnership in the unfolding of treasures and trappings in life and in diabetes care.

The Savings of Engaged Diabetes Care

Briefly stated, the burden of diabetes care is defined not only as the challenges for healthcare providers to offer patients comprehensive management (Hirsch, 2003) but also as the overwhelming challenges that patients and families face. Accordingly, Hirsch (2003) indicated in a commentary to his colleagues that the current system of managing diabetes is dysfunctional and in need of significant change. Successful provider interventions, measured in productivity, don't always capture "making a difference" in the life of a patient or family. Evaluating the return on investment from a limited financial perspective is a dilemma. This vantage point does not take into account societal connections or who may be profiting from the increased prevalence of diabetes.

A summary of costs related to diabetes is consistently documented in the literature. Direct medical costs in the United States annually are approximately $116 billion and indirect costs total an estimated $58 billion. The medical expenditures for people with diagnosed diabetes are more than double those of people without the disease (Centers for Disease Control and Prevention, 2008). Direct cost measurement typically involves the cost of hospitalizations, office visits, medications, medical supplies, home health services, podiatry services, etc. The indirect costs involve lost productivity (for working and non-employed individuals), disability, mortality, and absenteeism and presenteeism (described as being at work but less than optimally productive).

According to the American Diabetes Association (2010c), by 2050, an estimated 48 million U.S. residents are expected to have diagnosed diabetes. Small changes in clinical status translate into financial gains proving that education and self-management in diabetes are favorable investments. For every $1 invested in self-management training it is estimated that health care costs may be cut by up to $8.76 (Centers for Disease Control and Prevention, 2010a). With appropriate primary care for diabetes complications, nearly $2.5 billion in hospital costs might have been avoided, resulting in a Medicaid savings of $386 million and $1.3 billion savings in Medicare savings (U.S. Department of Health and Human Services, 2005). Perhaps the paradigm shift from diabetes *management* to diabetes *care engagement* will begin to reveal consistent cost savings.

Future Energy in Nursing Praxis

In diabetes care, there is a call to nursing to step forward, to become visible, and to change the paradigm of *diabetes management.* There is no greater place in the discipline to exercise our innate, holistic world view; to work intuitively, *connecting and collaborating*; and to simply be present to individuals and families as they strive to *fit this disease into their lives.* Koerner (2007) defines cultural creatives (2007) as healers who "practice from an integrative view of themselves and the world" and proposes that they will be the ones to move us toward healing, wholeness, and transformation (p. 25). These are the intuitive, or *noetic,* nurses who possess an inner understanding of where we are fractured and where we need to made whole (Koerner, 2007, p. 26). The challenge now is to take the key learnings, the participant messages, and the insights specific to diabetes care management and disseminate them in a meaningful way while restoring and preserving the essence of nursing.

Each nurse brings her or his own *web* into each patient/family interaction and there exists a relationship of *webs.* Further research into the seven stages of consciousness (surviving, connecting, feeling, doing, knowing, being, and unifying), identified by Koerner (2007) as the central core of the *Healing Web* may lead to a revision of the *Energy Web.* Perhaps in returning to the interviews, and in future interactions with people and families affected by diabetes, the web work may reveal that the core spindles of Maslow's developmental stages (physical needs, safety/security, love/belonging, self-esteem, and self-actualization) may be replaced with those seven stages of consciousness. The *Energy Web* should be meaningful, genuine, easily integrated into practice, and that the tenets of social justice are evident as a critically fundamental aspect of the web.

This DNP project calls us to consider the potential need for a "care engagement model," rather than a "care management" model, specifically tailored for individuals with diabetes, pre-diabetes, and metabolic syndrome providing for enhancement of the "upstream determinants of health" that are concordant with the overarching healthcare reform efforts. Embracing a new paradigm of HEC will move us toward realizing this new way of thinking and being in the experience of type 2 diabetes for our patients and for us as caring professionals. It is nursing that understands what it is to journey beside our patients and as a profession we are called to unleash the power of the discipline and lead this endeavor in diabetes care in the greater arena of healthcare reform.

This is the "alpha" for an otherwise unheard, misunderstood population, and the hope is for a positive transformation toward effective diabetes care-engagement that knows no "omega." There are articles to be written with and for those with diabetes and those who care for them. There are schools of nursing to reach out to and share this commitment with. Our new nurses are our leaders and our patients are depending on them. Nursing gathers for conferences and seminars and there is usually a palpable energy that results. My hope is that we can create opportunities to share the message of "*Energy Webs* and Nursing Praxis: Patterning in the Lived Experience of Type 2 Diabetes." We can begin to create a thunderous whisper in the world of type 2 diabetes, breaking down barriers within our discipline, finding a common voice, calling for respectful insights, continuing to work tirelessly toward mutually established goals, and beginning to live the philosophy that we are all meant to live. It is then that the critical steps can be taken across the disciplines in a supportive journey together, with our patients and families, in a genuine spirit of synergistic *Energy Webs*.

Black Elk Speaks

And while I stood there
I saw more than I can tell,
and I understood more than I saw;
for I was seeing in a sacred manner
the shapes of things in the spirit,
and the shape of all shapes as they must
live together like one being.
Black Elk

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Appendix A

Invitation to Participate

Consider Yourself "Invited" If…

…you have type 2 diabetes
…if you are over 18 years of age, and
… if you would be interested in sharing your experiences
with a nurse researcher

This study will involve:

- ☐ 2-3 individual interviews (one hour each)
- ☐ Protection of all information in a confidential manner

To participate, please call:
Kate Glasenapp at 414-719-1717
Doctor of Nursing Practice Candidate
St. Catherine University
Nursing Department
St. Paul, Minnesota

The goals of this project are:

…to offer you the opportunity to share your story of living with type 2 diabetes

…to create a "shared story" of those affected by type 2 diabetes

…to bring a heightened awareness of the "untold stories" to health care professionals

…to create a favorable change in how all of us experience type 2 diabetes

Appendix B

Study Consent

THE THUNDEROUS WHISPER:
GIVING VOICE TO THE LIVED EXPERIENCE OF TYPE 2 DIABETES
INFORMATION AND CONSENT FORM

Introduction:
You are invited to participate in a research study investigating the life experiences of adults with type 2 diabetes. Kate Glasenapp, a Nurse Practitioner who is completing her doctor of nursing practice degree at St. Catherine University in St. Paul, Minnesota, is conducting this study. You were selected as a possible participant in this research because you are an adult over age 18 with type 2 diabetes. Please read this form and ask any questions before you agree to be in the study.

Background Information:
The purpose of this study is to gain insight into the lived experience of type 2 diabetes. Approximately 8-12 people are expected to participate in this research.

Procedures:
If you decide to participate, you will be asked to participate in 2-3 interviews. The interviews will be conducted at a location of your choosing. These sessions will be audio-taped and later transcribed by a professional transcriptionist. The transcriptionist will be clearly instructed to omit any personal identifying information to protect your confidentiality.

Initial Interview:

Anticipated length of session is 60 minutes

Informed consent is reviewed and signed.

The researcher will ask you to discuss 3 topic areas. The questions you will be asked are:

1. What are the most significant events of your life?
2. Tell me about your most significant experiences with type 2 diabetes?
3. Do you have any ideas or suggestions that you want shared with healthcare providers as they interact with people who are living with type 2 diabetes?

At the conclusion of the initial interview there is a short questionnaire you will be asked to complete.

Second Interview:

Anticipated length of session is 60 minutes

Conducted within 2-3 weeks of initial interview

Your willingness to continue your participation in the study will be confirmed

The researcher will ask you to review a summary of the initial interview giving you the opportunity to:

- clarify the information
- add information or continue the discussion from the first interview

If you feel that you have had sufficient opportunity to discuss the 3 topic areas by the close of the second interview, no third interview will be necessary.

Third Interview:

Anticipated length of session is 60 minutes
Conducted within 1-2 weeks of second interview
Need for a third interview will be your decision as a participant
The focus remains on the 3 topic areas outlined at the initial interview

Summary Session:

An optional, informal group gathering of participants and non-participants who are affected by type 2 diabetes will be held at the conclusion of the study, anticipated in May 2010. The purpose of this group meeting is to review the study summary prepared for presentation at the St. Catherine University and for healthcare provider groups in the future. You will receive an invitation to the gathering by your choice of phone, mail, or email, if desired.

The Summary Session is optional and open to you whether or not you participate in or complete the study. You will be asked your preference in terms of notifying you of the Summary Session. There is no obligation to attend.

Risks and Benefits of being in the study:

The study has minimal risks. Some people have histories of struggles in their lives and in their experience with type 2 diabetes. This may cause people to become uncomfortable or emotional and to have difficulty talking about their experiences. You have the option to "not discuss" certain topics or to end your involvement in the study at any point.

It is anticipated that you will view your participation in the study as a positive one that allows you to tell your story of living with diabetes. Sharing the results of this study with others living with type 2 diabetes and their providers may improve the experience for both patients and health care professionals.

Confidentiality:

Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable.

The researcher will keep the consent forms in a sealed envelope in a locked file cabinet. The audiotapes and research results will be kept in a separate secure place that only the researcher has access to. The researcher and faculty advisor will both have access to the transcriptions and study information throughout this project. The study will be completed by May 2010. At that time the audiotapes and transcriptions will be destroyed.

Voluntary nature of the study:
Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with your health care provider, your clinic, or St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

Contacts and questions:
If you have any questions, please feel free to contact the researcher, Kate Glasenapp at 414-719-1717. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Margaret Dexheimer Pharris 651-690-6572, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of St. Catherine University Institutional Review Board, at 651-690-7739.

You may keep a copy of this form for your records.

Statement of Consent:
You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time.

I consent to participate in the study and I agree to be audio-taped.

Signature of Participant Date

Signature of Researcher Date

Appendix C

Participant Questionnaire

Participant #______

The Lived Experience of Type 2 Diabetes Questionnaire

Please answer the following questions as best you can:

When were you diagnosed with type 2 diabetes? ____________________________________

What 3 words would you use to describe your experience with diabetes?

1)___________________ 2)_____________________ 3)______________________

What is your age? ___________ What is your sex? ____Female ____Male

Do you take pills for diabetes? ____Yes ____No

Do you take insulin for diabetes? ____Yes ____No

Do you take herbal remedies for diabetes? ____Yes ____No

Do you take your diabetes medicine regularly, as ordered by your health care provider?

____Yes ____No ____ My healthcare provider did not order medicine for my diabetes

How often do you test your blood sugars at home?

____ Never or less than once a month

____ times per day

____ times per week

____ times per month

Select ONE of the following 3 statements concerning blood sugar averages:

______ 1) I don't know what an A1C or 3-month blood glucose average is.

______ 2) I don't know exactly, but my A1C or 3-month blood glucose average is usually: ____Over 10% ____8-10% ____in the 7% range ____Less than 7%

______ 3) My A1C or 3-month blood glucose average is _____%

Additional questions:

Who do you consider your “support”? (Include their relationship to you)

____

____

____

List any other illnesses or medical problems you have:

1. ____________________________ 5. ____________________________
2. ____________________________ 6. ____________________________
3. ____________________________ 7. ____________________________
4. ____________________________ 8. ____________________________

Use this space to include anything that you want the researcher to know about you and/or your experience with type 2 diabetes:

____

____

____

____

____

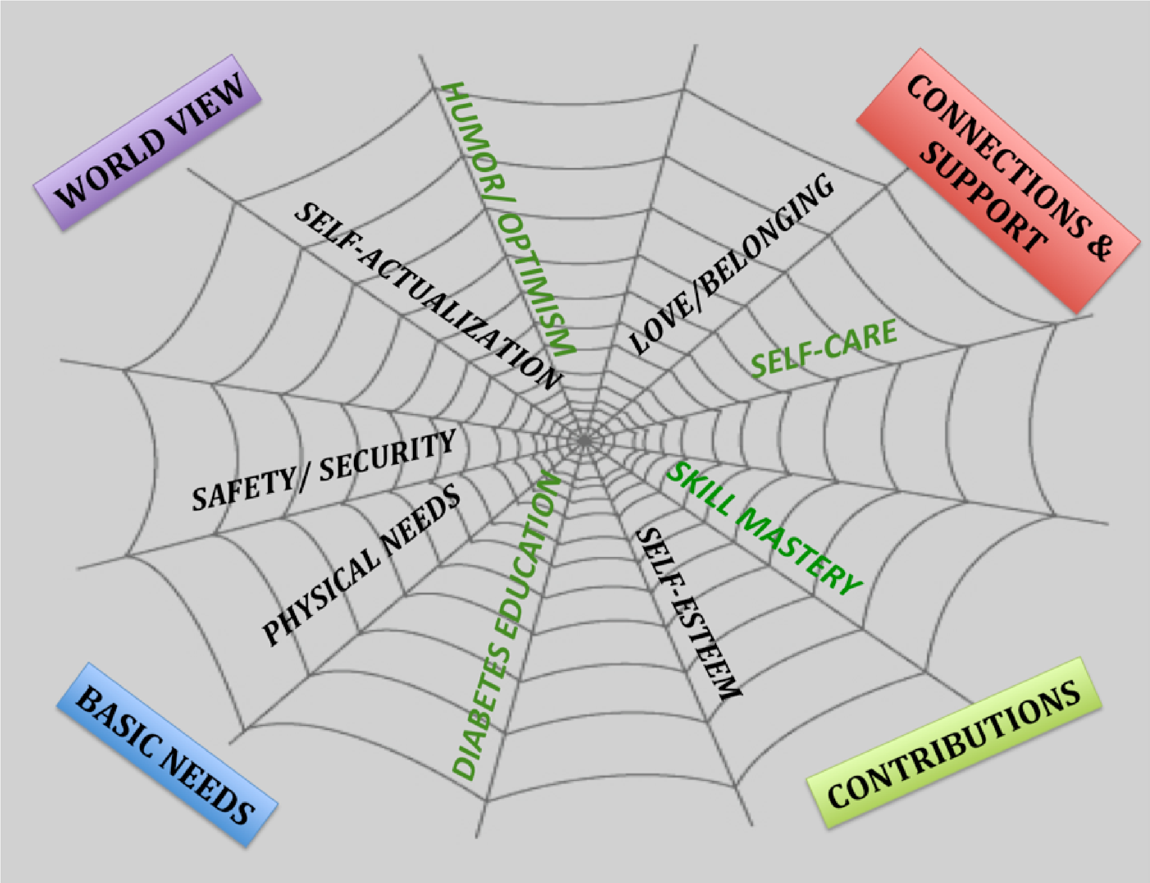
____

____

Thank you for taking the time to fill out this questionnaire!

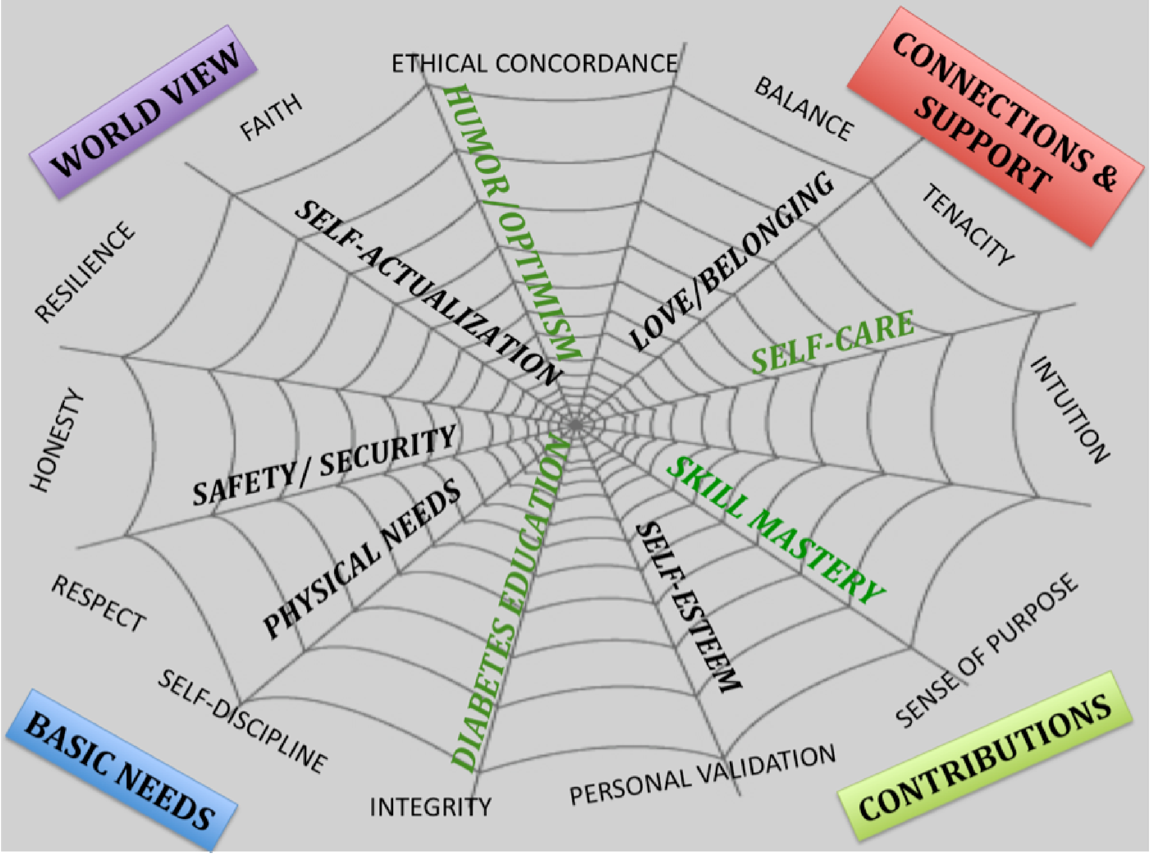
Appendix D

Energy Web with Anchors, Developmental Work, and Work of Diabetes



Appendix E

Energy Web: Virtues Added



Appendix F

Energy Web Choice Points: Treasures and Trappings