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LIVING WITH AORTIC STENOSIS: A PHENOMENOLOGICAL STUDY OF  
PATIENTS' EXPERIENCES AND SUBSEQUENT HEALTH CHOICES

A Thesis Presented

by

Gayle A. Hagen-Peter

to

The Faculty of the Graduate College

of

The University of Vermont

In Partial Fulfillment of the Requirements  
For the Degree of Master of Science  
Specializing in Nursing

May, 2015

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## Abstract

Symptomatic aortic stenosis (AS) is an increasing phenomenon as more adults live longer. The gold standard for treating AS is surgical aortic valve replacement (SAVR). Frequently, as older individuals with AS often have multiple comorbidities, a SAVR is determined to be too high risk. Therefore, a less invasive treatment option is available, namely a transcatheter aortic valve implantation (TAVI) or transcatheter aortic valve replacement (TAVR). Such biomedical procedures have encouraged life extension and the decision to intervene commonplace with the aging population. Without an intervention, significant debilitating symptoms affect a person's quality of life (QoL). Multiple quantitative studies evaluating QoL before and after a TAVI have been performed. However QoL has multiple attributes and is not a single construct. By limiting practice to these defined QoL measures, we exclude the human experience and what values individuals describe as important to them. The dilemma in the present medical model is influenced by two paradigms, evidence based medicine and patient centered medicine.

Some people opt not to have a TAVI. This study aims to understand what it is like living with aortic stenosis as perceived by the participant and to gain a more meaningful understanding of why some individuals with AS choose not to have this procedure performed. Using a convenience sample of patients who declined a TAVI, a telephone interview with the person focused on their perceived QoL and the implications determining not to pursue a TAVI. In this qualitative phenomenological design, open-ended questions included: 1) What is it like to live with Aortic Stenosis. 2) Why did you choose not to have the TAVI? Interviews will explore emerging themes. Advanced practice nurses are in ideal positions for performing research to gain greater insight on the complexity of people's health choices. As the incidence of AS occurs more frequently in the increasing aged population, TAVI offers a treatment option for those patients who are symptomatic with AS and are not surgical candidates. However, health care providers should focus on the illness, not the disease, and explore the patients' biopsychosocial values with their medical needs. The information gathered in this study will help guide health care providers with offering holistic health care incorporating both paradigms of evidence based practice and patient centered medicine options on treatment for people with symptomatic AS.

## **Acknowledgements**

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Additionally, I give thanks to my extraordinary committee members for their guidance throughout this research. My committee advisor, Dr. Sarah Abrams, provided unwavering mentorship, knowledge and expertise in nursing research. I am appreciative of the support and guidance received by Dr. Judy Cohen. I wish to thank my committee chair, Dr. Bruce Leavitt for his encouragement and clinical expertise.

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## **Introduction**

Aortic stenosis (AS) is the most common valve disease in the United States (U.S.) (Nugteren & Sandau, 2010) affecting 2.8% of adults over the age of 75 (Go et al., 2013). According to the U.S. Census Bureau (2014) there will be 47.8 million people older than 65 projected in 2015. This cohort will rise to 88.5 million by 2050 and an estimated 3.5 million people will be living with AS by 2020 (Horrocks, Closs, & Astin, 2013). The population of aging adults is increasing due to better health initiatives, and medical interventions parallel the increase incidence of AS in the growing aged population.

Aortic stenosis is the narrowing of the aortic tricuspid valve orifice producing constricted outflow from the left ventricle causing left ventricular hypertrophy. This compensatory hypertrophy contributes to debilitating symptoms including exertional dyspnea, angina, syncope, orthopnea, paroxysmal nocturnal dyspnea, fatigue, and exercise intolerance, many of which affect people's quality of life (QoL) (Charlson, Legedza & Hamel, 2006).

Although surgical aortic valve replacement (SAVR) is optimal, there are inherent risks with cardiopulmonary bypass and aortic cross clamping. This operative risk along with patients who have significant comorbidities is not appropriate for one-third of patients with AS (Iung et al., 2005; McRae & Rodger, 2012).

The transcatheter aortic valve implantation (TAVI) is offered as a safe and viable treatment option for symptomatic AS patients. The procedure entails an insertable valve placed using a percutaneous approach. The U.S. Food and Drug Administration gave

commercial approval of the TAVI for treatment of severe symptomatic and inoperable status in 2011 and high risk but operable status in 2012 (Mack et al., 2013).

The decision to undergo the TAVI procedure is complex. Along with mortality and hemodynamic valve performance, determinants addressed in the preliminary work up are functional health status including evaluation of quality of life (QoL). Multiple quantitative research studies have been performed investigating QoL before and after TAVI that show improvement in individuals' QoL as compared to standard medical therapy for non-surgical candidates (Bleiziffer et al., 2012; Krane et al., 2012; Reynolds et al., 2012; Shim, Russ, & Kaufman, 2006). Quality of life is not, however, a single construct but a blend of many variables (Ferrans et al., 2005). Many definitions describe functional abilities, sense of well-being, perceived physical capacity, satisfactory socioeconomic status, yet exclude the lived human experience or personal ethos in relation to their goals, expectations and concerns (Milton, 2013).

Quality of life measures have multiple dynamic attributes, definitions, labels, and categories, yet by limiting practice to these defined QoL measures we exclude human experience and the values individuals describe as important to them. Quality of life instruments are generally quantitative in design (Milton, 2013; Ward-Smith, 2011). Quantitative measurements poorly evaluate beliefs or values that patients may ascribe to QoL. The World Health Organization identifies quality of life as embedded in one's cultural, social, and environmental perspective of the individual's perception of their life in relation to personal goals, expectations, standards and concerns (WHO, 2012).

The decision to have a TAVI is presently influenced by two paradigms in the medical care model, evidence-based medicine and patient-centered medicine. The evidence-based medicine concept, introduced into scientific literature in the 1990s, gained popularity as clinical expertise and scientific research offered evidence toward high quality treatment. This positivistic, biomedical perspective (Bensing, 2000) directs the clinician focus toward treatment options with little influence of the patients' uniqueness and preferences in the clinical decision making process. According to Shim, Russ & Kaufman (2006) medical practice defines clinical ethics rather than ethical-decision-shaping practice. The resurgence of patient-centered medicine involves the biopsychosocial paradigm with focus on including a patient's participation in clinical decision-making. However, empirical evidence for this practice is limited because the underlying concept is multi-dimensional and therefore difficult to test.

Although research supports the use of the TAVI procedure to reduce mortality and morbidity (Holmes et al., 2012; Reynolds et al., 2012, & Thourani et al., 2013) the focus of most research is based on an assumption that greater quantity of life is the ultimate patient goal rather than acceptance of a reduction in life expectancy with the goal of determining the direction of remaining life. With more frequency, many people are offered medical interventions aimed at prolonging life. The increase in life-prolonging intervention suggests that such biomedical possibilities are germane for elderly individuals (Shim, Russ & Kaufman, 2006). Yet, there is an ethical dilemma between the pursuit of biomedical interventions and the discussion of ultimate personal goals. By not

substantiating the personal goals of an individual, we ignore the patient's approach to aging and dying.

Greater pursuit of medical interventions necessitates understanding that each person is inherently different when choosing personal health in finding meaning related to their quality of life. Making health care choices is not a numerical or objective equation determined by an algorithm, rather a myriad of unique values to which an individual ascribes. Only individuals can rate their personal QoL because "quality" is highly subjective representing individual values that are inclusive of physical health, psychological health, level of independence, social relationships, environment, and spiritual and personal beliefs. The choice of quantity of life as a goal is an option, but information limited to quantity is often insufficient for people to make an informed treatment decision. Although the TAVI procedure is a novel option for patients with symptomatic AS, the decision-making process should include relief of aortic stenosis related symptoms as well as an individual's values that determine their quality of life.

Because of prolonged life expectancy, health care providers will see more people with symptomatic AS. A model of ethical practice should be the blend of evidence-based medicine and patient-centered medicine. By understanding the patients' values we can integrate the biomedical and social science paradigms. An approach to identification of treatment options is valuing the patient's personal goals with informed decisions by the patient.

As nursing is one of the most trusted professions (Milton, 2013), we have the opportunity to influence QoL research with the focus on holistic well-being. According to

the International Council of Nurses (2012) inherent nursing values include respecting human rights, the right to life and to be treated with respect, as well as others. The American Nurse Association Code of Ethics for Nurses with Interpretive Statements (2015) identifies respect for human dignity and the right to self-determination therefore illuminating ethical principles that direct the profession of nursing.

### **Why is the problem worth exploring?**

Making health care decisions is a complex process (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Milton, 2013). Providers need to include and honor a person's experience and self-perceived QoL when making subsequent choices in health care decisions. The selection of people used in this study is optimal because of the inherent poor prognosis and rapid disease progression of AS. According to Holmes et al. (2012) a patient's decision for treatment of AS ultimately should be a shared decision among the informed patient, family and provider. The goal for optimal health care decisions should include medically reasonable options for treatment that match a patient's values, goals, and preferences (Allen et al., 2012). Health care providers should focus on the illness, not the disease, and explore patients' biopsychosocial values in concert with their medical needs. Only when we incorporated the patient's wishes, can we provide holistic quality care (Gardiner, Wilson, Ingleton, & Gott, 2013; Milton, 2013).

### **Relationship to Advanced Practice Nursing**

Because of increasing life expectancy, advanced practice nurses will be seeing more people with symptomatic AS seeking information about the disease process and

treatment options. As advanced nurse practitioners represent approximately eight percent (Naylor & Kurtzman, 2010) of the nursing workforce, there are profound implications for practice in the chronically ill and elderly populations. The American Academy of Nurse Practitioners (AANP) (2015) practice model's priority is placed on patient and family education and facilitating patients participation in self-care.

Based on nurse practitioner's education and expertise, nurse practitioners should be on the forefront of evolving health care. This has profound implications for APN practice as nurses are in a position to provide education, guidance, and treatment options for the promotion of health and therapeutic modalities for patients along the AS disease process.

### **Theoretical Framework**

Sister Callista Roy's Adaptive Model posits that understanding the impact of chronic illness and well-being integrates the biological, social, and psychological complexities of older people's lives. Roy's Adaptive Model fosters variation for individuals' psychological needs, concept of self, roles and inter-dependence with others, which contributes to health, quality of life, as well as dying with dignity. By assessing factors that influence adaptive abilities, one can enhance the ultimate goal of achieving dignity and integrity.

Using an interactive process of Roy's theoretical framework, ethical enquiry, combined with Heidegger's phenomenology allows the researcher to identify emerging themes. The ontological view that multidimensional realities exist which are influenced

by many internal and external forces, offers integrity and meaning to the patient's choice to have a TAVI procedure or to choose a more palliative option.

Roy's Adaptive Model provided the theoretical framework for this study because the focus is on identifying factors that affect the quality of life of elderly AS patients and her understanding that health and illness are inevitable dimensions of the person's life. These findings provide an initial direction for further theory enhancement and suggest that there should be a focus on the development of nursing research that include physical and psychosocial variables with elderly aortic stenosis patients.

## **Review of Literature**

The diagnosis of AS is increasing in the U.S. population due in part to the aging of the population. The urgency of studying older adults' treatment decisions is predicated upon a concern about the ethical practice implication of two main streams of health practice, one based on preservation of life, the other on the personal preferences of patients. The organization of this review is the prevalence, pathology, treatment modalities and inherent risks of treatment, TAVI determinants of QoL, and the ethical dilemma created when using present tools to assess QoL in aortic stenosis. A search of literature yielded eleven studies that were directly relevant to diagnosis, treatment and management for TAVI procedure, five studies pertinent to management of patients with valve disease, eight studies addressing QoL indicators in patient with valvular disease, and six recent discussions of the ethical imperatives of treatment verses no treatment, six studies germane to decision making and end of life discussions, and two related to phenomenological study. The time frame incorporated 2005 to 2015.

### **Prevalence**

The prevalence of Aortic Stenosis has been widely identified. Nugteren and Sandau (2010) note AS is the most common disease in Europe and in the United States. Annually the American Heart Association (AHA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) gather the most up-to-date statistics on heart disease, stroke, other vascular diseases, which is reported in the Heart Disease and Stroke Statistical Update (Go, et al., 2013). The 2014 Update notes the prevalence of moderate or severe aortic stenosis in patients  $\geq 75$  years old is 2.8% (95%

CI, 2 .1%–3 .7%) of the US population. These staggering numbers will be increasing with the increase of life expectancy. According to the American Heart Association 2014 statistics, 1.5 million people in the United States (US) suffer from symptomatic AS, without surgical or procedural intervention, half of those patients will die within two to three years following the onset of symptoms (Bach, 2011; Nugteren & Sandau, 2010) and prognosis with medical management alone is poor (Go et al. 2014; Held, 2012; Nishimura et al., 2014; Webb et al., 2012). These implications are important for two reasons. Providers will see more patients with AS and patients who choose not to be treated, will have a shorter life span. Understanding and awareness of age related changes, such as increased risk for comorbidities and decrease in homeostasis capacity, is an essential part for elderly in determining treatment modalities.

### **Pathology**

Causes of AS have been extensively described in literature. Eighty percent is due to natural progressive valvular calcification of the tricuspid aortic valve of the aging person (Rayner, Coffey, Newton, & Prendergast, 2014), other etiologies are congenital valvular abnormalities and rheumatic fever. Degenerative aortic valve stenosis (AVS) rarely becomes symptomatic before age 70, an age where comorbidities are often a combined factor. The progressive debilitating symptoms impact one's QoL and contributes to people seeking treatment options for AS (Panos & George, 2004).

### **Treatment/Associated Risk**

Surgical aortic valve replacement (SAVR) is the gold standard treatment for symptomatic AS (At-Attatr et al., 2009; Bleisiffer et al., 2012; Walther, Kenmfert, &

Mohr, 2012). Unfortunately, due to the high morbidity and mortality associated with surgical AVR and the increased risk of comorbidity in patients who have AS, some are deemed extremely high-risk surgical candidates therefore the condition may be considered inoperable (Held, 2012; Webb et al., 2007; Zierer, Wimmer-Greinecker, Martins, Moritz, & Doss, 2008). For inoperable patients with severe AS and significant comorbidities, the TAVI procedure is a less invasive and risk alternative (Al-Attar et al., 2009; Cohn & Narayanasamy, 2007; Walther, Kempfert, & Mohr, 2012). A Transcatheter Aortic Valve Implantation (TAVI) is the replacement of an aortic valve using an endovascular approach via transfemoral, transapical, transaortic, or transcarotid access. The TAVI alternative procedure to open heart surgery for those with severe symptomatic AS has become a standard therapy for high-risk elderly patients (Walther et al., 2012). Since the first TAVI implantation in 2002, multiple studies have been conducted to examine improved survival of elderly patients with severe AS. The Placement of Aortic Transcatheter Valves (PARTNER) Trial, a large multicenter randomized control study, evaluated the TAVI versus AVS and the TAVI versus medicine treatments. The PARTNER A Trials' data determined the two-year mortality of those who had a TAVI procedure was 33.9% as compared to patients who has a surgical AVR at 35%. The PARTNER B cohort was basing the two-year mortality on TAVI verses medical therapy, was respectively 43.3% and 68%. (Go et al., 2014). These research conclusions, while statistically significant for morbidity and mortality from the biomedical medical perspective, don't elicit the uniqueness of patient's perspective in patient-centered medicine.

As with any procedure there are some risk factors inherent with TAVI including, myocardial infarction, cerebral vascular events, acute renal insufficiency, major vascular injury, bleeding, emergent SAVR, paravalvular aortic regurgitation, acute renal injury, new onset atrial fibrillation, the need for a pacemaker or implantable cardioverter-defibrillator, and death (Al-Attar et al., 2009; Charlson, 2006; Mack et al., 2013). In a study by Tamburino et al. (2011), mortality results from 663 consecutive post-TAVI patients in 2007 through 2009 were 15% at one year after procedure. These risk factors presented to potential candidates for the procedure may contribute to individuals' decisions to forego a TAVI. This predicates the question of why there is a need to know how people come to a decision about refusing TAVI.

### **Quality of Life Assessment**

Concurrently there is a growing body of literature validating improvement in QoL following a TAVI. The current research measures physical functioning, symptoms, self-efficacy, role limitation, bodily pain, general health, vitality, social functioning, and mental well-being. The PARTNER Trial used the Kansas City Cardiomyopathy Questionnaire (KCCQ) and the 12-item Short Form-12 General Health Survey (SF-12) to assess the patient's perspective of their health status (Bloomer, 2011). Other quantitative tools used are, European System for Cardiac Operative Risk Evaluation (EuroSCORE) (Marion & Rodger, 2012; Reynolds et al., 2012), EuroQOL group EQ (Reynolds et al., 2012), Health Related Quality of Life (HRQOL) (Nugteren & Sandau, 2010), and Medical Outcome Trust Short Form 36-Item Health Survey (Krane et al., 2012; Bekeredjian et al., 2010). One year following TAVI, Bekeredjian et al. (2010) noted a

“significant improvement” in QoL health components, Reynolds et al. (2012) provided numerical improvements in all three of their QoL assessment tools, and Krane et al. (2012) results determined a significant QoL improvement.

### **Ethical Dilemma**

These findings must be interpreted with caution however, by virtue of using quantitative measures typical of the study design. An interesting point noted by Milton (2013) is in using such tools to define QoL doesn't incorporate the individual's lived experience and lacks identifying that each person's qualities are inherently different. Milton (2013) believes that making healthcare choices should not be a numerical, objective evaluation determined by an algorithm. Although health is the “absence of disease” from the biomedical perspective, the WHO (1946) recognized health as “ a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity”. Quality of Life needs to reflect the multidimensional construct of people as it has profound implications for health care practices.

There is a shift in the understanding of what constitutes quality health care. Health care decisions require integration of research evidence and individual preferences. According to Bensing (2000) there is an ethical dilemma between the pursuit of biomedical possibilities, in other words evidence-based medicine, and the humanistic biopsychosocial perspective of patient-centered medicine. The enhancement of clinical expertise and scientific evidence offers highly technological treatment options yet medicine is founded upon the assumption that what needs to be known can be empirically shown and attributed to pathology. Yet nursing is defined by its emphasis on human

responses to illness or disease. An inherent value of nursing for human rights includes qualities of respect, compassion, and genuineness. Snellmand and Gedda (2012) note two ethical principles define nursing, the principle of human value and the right to experience a meaningful life. The International Council of Nurses (ICN) Code of Ethics (2012) emphasizes the nurse's role to give information to support informed consent as well as the philosophy of nursing is to respect human rights and dignity. The IOM asserts that to provide high quality of care, it should be patient-centered. It is imperative that quality of care should include both clinical and experiential aspects of care as viewed from the patient's perspective of their illness and its impact on his or her life.

The diversity of patients' unique experiences, needs, and preferences are overshadowed in clinical decision-making. The paradox of evidence-based medicine, as noted by Bensing (2000), is important as it offers high quality of care yet it lacks the uniqueness of each patient included in patient-centered medicine. Decisions on health care should be individualized as individuals may view choices between options and outcomes differently. Shim, Russ, & Kaufman (2006) examines the recent shift in how health care providers think about treatments, how older individuals conceive of themselves and their own aging, and how as a society the pursuit of medical treatment to maximize late life. An interesting point in their article delves into the pursuit of biomedical interventions to prolong life is altering the way we look at ageing and death.

Although TAVI is an innovative technological procedure for high-risk surgical patients, not all patients want to undergo this procedure. There have been a large number of qualitative research studies conducted to measure mortality, morbidity and QoL.

However, very few include subjective data examining people's reasons for choosing not to have the TAVI. Go et al. (2014) identified 50% of patients with severe aortic stenosis see a cardiothoracic surgeon and approximately 40% undergo AVR, the reasons for not undergoing AVR included high perioperative risk, age, lack of symptoms, and patient/family refusal. Bach, 2011, cites reasons for not undergoing AVR were comorbidities or high operative risk, advanced age or limited life expectancy, asymptomatic status, and patient or family refusal. Neither of these articles elaborated on the "patient and family refusal". In this literature search, the researcher was unable to find articles that addressed reasons for not pursuing a TAVI.

Previous research tools, predominantly a self-administered questionnaire to determine one's QoL, have limitations as noted in this study. While there is a significant amount of quantitative research done on QoL measures, this study will focus on a qualitative approach to obtain a better understanding of what it is like living with symptomatic aortic stenosis and what themes evolve with those who decline to proceed with the procedure. There is a gap in literature of elderly people with multiple comorbidities comparing procedural treatment versus conservative management. A research of elderly people with comorbidities in chronic kidney disease, cancer and congestive heart failure found few similarities but many variables differ dramatically from AS patients. A recent article in the Journal of Clinical Nursing by Harwood & Clark (2014) summarizes that elderly chronic kidney disease patients' decisions are influenced by health status, gender, knowledge, values, beliefs, past experiences, and preferences. Although the determinants are similar, the time frame from cessation of dialysis to death

is six to eight days (Fissell et al., 2005). As noted previously, from the first symptoms of AS to death is approximately two years. Another cohort that is similar regarding declining treatment is a patient with cancer. Radley and Payne (2009) report that decision making for cancer patients is individualistic and should be supported by accepting alternative values on how the meaning of life is addressed. Again, the extreme variability in cancer prognosis may alter the decision process. There are many studies evaluating decision making in congestive heart failure patients but this differs from AS as interventions are medicinal rather than procedural.

As TAVI becomes increasingly accessible and indication for its use expands, it is important that nursing researchers recognize the gap that exists and extend research to understand and include the personal choices of patients with aortic stenosis. Patient-centered medicine indicates that health care providers direct their attention to the illness, not the disease. Guiding patient-centered decisions about making health care decisions should include evidence-based medicine with patient-centered medicine, incorporating the patients' values, goals, and preferences.

### **Purpose of the study**

There is a gap in research about what is important to people with aortic stenosis when making health care decisions. Qualitative research will help address the gap to encompass the patient's perspective as domains that are important to their health decisions. By utilizing the richness and depth of qualitative research, the aim of this study is to illuminate the subjective meaning of the complex phenomenon of the lived experience of the person with AS and his or her decision not to seek medical intervention.

Two main research questions will be addressed:

- 1) What is it like living with AS?
- 2) Why did you choose not to have the TAVI procedure?

Obtaining a richer understanding of the complexity of people's choices for treatment options, health care providers can support older adults' decision-making with dignity and autonomy. Incorporating the knowledge learned from this study, nurse practitioners can better understand the patient's decision to decline having a TAVI.

## **Methods**

### **Design**

In this exploratory qualitative study, the researcher used a phenomenological approach utilizing interviews conducted with elderly people living with aortic stenosis. Using the richness and depth of qualitative research permitted fuller understanding of the complex phenomenon of what leads to a person's decision not to seek medical intervention as experienced by the patient. A convenience sample of participants from a medical and teaching hospital in the northeast was obtained. To capture the rich account of each participant's expert knowledge and experience of living with aortic stenosis, open ended questions during the interview included 1) What is it like living with AS? 2) You decided not to have a TAVI procedure, tell me about that decision. This open-ended style encouraged the participants to take the lead in telling their stories. If the answers were limited, participants were encouraged to elaborate on their shared descriptions.

### **Sample**

A list was obtained from the cardiology team at a medical and teaching hospital in the northeast of people with severe, symptomatic aortic valve stenosis who were not surgical candidates for an aortic valve replacement and declined to have the transcatheter aortic valve implantation. The time frame for the study commenced January 2013 through January 2015. A convenience sample from the list included those who agreed to participate in the research. We anticipated approximately six individuals would take part in this study.

Following approval by the University of Vermont and the Hospital's Institutional Review Board, the researcher contacted the TAVI cardiology team by email. An overview of the thesis on TAVI was provided as well as explanation of the thesis as part of the graduate requirement for the Master of Science Degree as an Adult Nurse Practitioner. The researcher requested the name and contact number of participants who elected not to have the TAVI from the hospital's TAVI database. The database is inclusive of all patients referred to the TAVI team for the procedure since the hospital obtained approval to perform TAVI's in 2012. From this database, the researcher obtained the names of participants who declined to have the TAVI from January 2013 to January 2015. Once the sample was obtained, the Adult Nurse Practitioner on the TAVI team mailed an Introduction Letter (appendix A), a Research Informational Sheet (appendix B), and a Consent Form Update (appendix C) introducing the researcher, an overview of her thesis proposal, and informed the participants to call her for questions or to decline participation in the study. From those who did not decline to be part of the study, the researcher followed up with a telephone call in 7-10 days from the date the letter was mailed, and if the participant was interested, offered to schedule a meeting in the person's home or conduct the interview by telephone.

### **Data Collection**

Consent was inferred if the participant agreed to participate in the study following review of the Research Informational Sheet. The interview was conducted by telephone, and audiotaped to obtain a true account using the participant's own words. At the beginning of the interview each participant was offered the opportunity to ask questions

and was reassured of their anonymity and the confidentiality of data obtained. No real names were used. Participants and records were coded with a confidential name for the purpose of maintaining confidentiality. Records were kept in a locked file at the researcher's home and on a secured computer network and were accessible with a password only known by the researcher.

Maintaining effort to follow the principles of phenomenological inquiry and ethical inquiry, interviews were flexible and responsive to context to encourage participants to speak freely.

Field notes were recorded within one hour of interview completion including tone of voice, eagerness or reluctance to engage, supportive family members present, and reflections and interpretations.

### **Data Analysis**

According to Barnett (2005) data analysis in phenomenological research begins during data collection with active listening, reflection, clarification and intuiting. Using the philosopher Martin Heidegger's interpretive phenomenological methodology, the researcher explored themes of why some people choose not to have the TAVI procedure. According to Heidegger, the ontological view on the nature of being and meaning of the lived experience has a larger meaning in being and more breadth than what we can see (Dowling & Cooney, 2012). Following Heideggerian hermeneutic research, the data obtained provided the researcher an understanding of what it is like to live with aortic stenosis as described by participants, and upon data analysis, comments were gathered that evolved during the interviews. Audio recordings of the interview were transcribed

verbatim using Dragon Dictate software program. Transcripts were read and reread. Information was classified, indexed, and categorized into similar concepts. It is important to note that this was not a linear process, but a continuous review and iterative process.

To provide a good level of rigor to fortify trustworthiness, a method of analysis was included: a transcriptionist was hired and contents reviewed by the researcher twice, reading all transcriptions for an overall understanding, writing interpretive summaries, analyzing transcriptions as a group to identify themes, and comparing and contrasting texts to identify, describe and interpret consistent meanings. Auditability was maintained with organization of two audio recordings, transcripts, field notes, and codes. The audit trail established trustworthiness and confirmability. The author provided rich contextual narrative to preserve the uniqueness of each participant's lived experience and allow understanding of the phenomenon investigated.

The researcher holds no presumptions that this study represents all people who make the decision on the TAVI intervention, rather offer insight to understand why some choose not to have a procedure that is purported to expand their longevity and improve their quality of life.

## **Results**

There were 75 potential subjects during the time frame of January 2013 to January 2015. From the 75 initial subjects 19 have deceased, 16 had the SAVR, 5 had the TAVI, 16 didn't meet criteria due to multi-factorial reasons, failed memory, alcohol abuse, non compliance, and 13 were excluded for various reasons. The remaining eight people who met the study criteria were sent letters. Of the eight participants one had deceased, one declined, two did not return a call following three telephone calls with messages left, leaving four participants who agreed to be interviewed. The four participant's age range was 82 to 89 years old (Mean = 84.5). Two participants were female and two were male. The names were changed to protect the identity of these participants. The duration of the interviews were between six minutes and thirty-four minutes. Participants varied in willingness to elaborate on discussions, some were reluctant to expand on responses while others were more willing to share details.

Themes identified during telephone interviews included independence, fear of unknown prognosis and sources of support. The data are presented through the use of quotes of the participants on questions asked, what is it like to live with aortic stenosis and what factored into your decision not to undergo a TAVI.

### **Independence**

Three of the four participants remarked on shortness of breath and their individual functional ability. Perception and evaluation of symptoms entails multiple factors that characterize the symptom experience. The natural progressive disease process in patients with aortic stenosis predominantly causes increased shortness of breath.

I don't feel bad. I'm not really short of breath, only when I exert myself, but that could be my age. (Mrs. Sachs)

Well, right now I feel fine. I mean, I felt good for quite a long time so I never went back to see (the doctor). Well, I get tired, but I don't get out of breath or anything. (Mrs. Bernard)

I don't know I have it (AS) until I go to the doctors and they remind me. My breathing is no worse than it's been for years. (Mr. Spark)

As the disease progresses, quality of life and one's ability to maintain daily and social activities is a significant factor influencing the participant to pursue treatment options. The functional limitations the participants mentioned were due to their comorbidities rather than aortic stenosis symptoms.

I have a very active lifestyle, I go to physical therapy three times a week...I have doctor's appointments, and I go out to lunch some times. My hip needs replacing but I go to physical therapy, that's the only thing that bothers me. (Mrs. Sachs)

I can do my work and I can go shopping, I can do things like that. No heavy stuff. No it's not so bad (arthritis), that's what I can't understand. It isn't as bad as it

was when I was younger, and you would think it would be, now that I'm older that it would be worse. It isn't. (Mrs. Bernard)

I am too active right now. I volunteer at the hospital two days a week and two days a week at residence. I go to bingo every Monday and Tuesday. I love Church Street on weekends and other days in good weather. I'm walker dependent, rehab would be difficult. (Mr. Spark)

Three of the four participants expressed living in their home as important. Values differ between individuals as degrees of importance vary with tradeoffs that may occur with their decision.

I want to stay in my home as long as I can. (Mrs. Sachs)

Well she (the doctor) said that after all of that I might eventually have to end up in a nursing home, and that *did it* [emphasis added]. I have my own home and I'd like to stay in it as long as I can. (Mrs. Bernard)

I don't want anyone taking care of me. I'd rather not live. (Mr. Landry)

## **Fear of the unknown**

All participants in this study noted living with AS presently was favorable over the possibility of post procedure morbidity and mortality and family as a source of support and comfort. Living with known disabilities was acceptable, whereas the potential risk for stroke, dialysis or death was a strong influence in determining not to have the TAVI procedure.

They said I would be on dialysis if I had this. I don't want to live dependent on a machine, that's no way to live. (Mrs. Sachs)

If I had to sit in a chair all day or lay in bed all of the time I wouldn't like that either, I want to be able to do something. Well, I can't live like I used to, I mean, I can do the best I can. (Mrs. Bernard)

First they give you a pamphlet over there [at the cardiologist's office] and it tells you that it may cause you to have a stroke or to die. I think there's something like, I don't know, a 30% chance of dying and a 10% chance of having a stroke. That was written in a pamphlet, so that's why I decided not to have it. I don't want to have a stroke or be paralyzed or have someone take care of me. (Mr. Landry)

I don't want to have a stroke and be in bed forever. (Mr. Spark)

Prognosis is a variable inherent to any procedure. For a person to make an informed decision to have the TAVI procedure, information provided by the provider included disclosure of relevant risks, benefits, and uncertainties related to treatment options. A remark not to pursue the TAVI as reported by Mrs. Sachs, “The doctor couldn’t give me any guarantees.” Mrs. Bernard noted, “I decided that I didn’t think I wanted to do it because after all that stuff (pre procedural workup) that the procedure might not work. I just can’t see going through all that stuff then it probably wouldn’t do anything anyway.”

### **Source of support**

Family is frequently a source of support and comfort. Three of the participants live with someone; a daughter, son or wife and one lives independently, and one has a daughter he sees multiple times per week. In this study, two participants mentioned family contributes to their being able to live at home and two noted the family provides socialization. One participant found support in a deity.

I go out to lunch with my daughter sometimes and she comes around a lot. (Mrs. Sachs)

I have a son that lives with me so he helps me out with things I shouldn’t do. He lives with me, he helps me out a lot. I don’t drive or anything like that so when I need to go shopping or need to go someplace he takes me. So that works out good. (Mrs. Bernard)

My wife and I get around. She can help me with the things I can't do. (Mr. Landry)

I live alone but one daughter lives in the area and I see her a few times a week. (Mr. Spark)

I'm 85. I've lived a good life. I guess I leave it in God's hands when it's my time to go. (Mrs. Sachs)

Implications of these interviews are discussed in Chapter 5.

## **Discussion**

### **Comparison to what is known/principal findings**

While the numbers of elderly people with chronic illness increase, how they choose what medical options they make is changing. Patient-centered care, a renewed concept, is beneficial for envisioning a new approach to advanced care planning. Patients' attitudes about using their own aims and values to make decisions should be included in their treatment options. Patient-centered care is defined as a partnership among patients, families and health care providers to design patient specific education and support to assist in making decisions that are respectful of the patient's needs and wishes (IOM, 2013).

The data from this study provided comments on what it is like living with AS from the patients' perspective. Three of the four participants reported shortness of breath symptoms as minor, having minimal effect on their daily life. This finding challenges other studies noting that dyspnea on exertion is the most common symptom of AS (Go et al., 2014; Bach, 2011; Horrocks, 2014).

All but one participant expressed their limited functional ability was due to comorbidities rather than the effects of aortic stenosis but their overall QoL was relatively good. The importance of quality of life is well recognized, but there is no single agreement of the definition of QoL. Ferrans, Zerwic, Wilbur & Larson (2005) argued that quality of life includes health status, physical functioning, symptoms, psychosocial influences, well-being, life satisfaction, and happiness variables yet the multiple variables hinder comparison of research conclusions and makes application to practice difficult.

According to Sousa & Oi-Man (2006) QoL is a multidimensional construct with multiple variables albeit without supposition about the associations between them. Milton (2013) reports QoL tools offer information on functional abilities but include little about the lived human experience. McRae & Rodger (2012) posit that nursing research is needed to improved utilizing health related QoL in the AS population.

Treatment choices for AS include SAVR, TAVI, or medical management, with or without a balloon aortic valvuloplasty. But some patients choose not to have the TAVI. This study aimed to identify themes about the decision to decline to have the TAVI by participants with AS. Making informed decisions about treatment options in patients with aortic stenosis should include comprehensive information with benefits and risks regarding surgical, procedural or medical management. But it is unclear how much influence is attributed to patients' preferences versus what is proposed to them by their provider or how much of their own beliefs and values are included in the decision making process. Shim, Russ, & Kuafman (2006) state that information proposing cardiac intervention by providers as routine with diminished procedural risks fuels the desire for intervention, therefore standard practice is replacing choice. The lack of clarity of how much is attributed to chronic illness patients' preferences in decision making is further supported by Winterbottom, Bekker, Conner, & Mooney (2012).

An expectation of the ANA's Code of Ethics for Nurses with Interpretive Statements (2014) is respect for human dignity, which includes self-determination of treatment options, including the choice of no treatment. Ethical responsibility incorporates informing patients of their health condition and treatment options, including

realistic prognosis, according to Radley & Payne (2009). Nurses have an ethical responsibility to insure a more proactive approach to enable patients to fully engage in discussion regarding AS treatment options.

There has been limited research published addressing collaborative decision making with patients with aortic stenosis. Similar themes found in this study, such as independence, fear of unknown prognosis and sources of support, are themes identified in CHF, cancer, and dialysis research. But there is little relationship between persons with these diseases and elderly people living with AS who choose non-procedural treatment options.

A variety of factors influenced the choice of these participants not to have the TAVI. Potential morbidity consequences, the risk of stroke or dialysis, were too heavy a burden for some to proceed with a TAVI. A determinant for two people was unknown prognosis. They would rather accept what lifestyle they presently live than to face an unknown health condition. The fear of loss of independent living, specifically in their own home, gave resolve to not proceed with the TAVI and defined living independently as the only option they wanted to live.

Sources of support by family offered companionship or a means to remain in their home. One person commented on “God” as a partial determination of her life expectancy. In other research with end-of-life cohorts, awareness of culture and religious differences can facilitate understanding in patient choices when discussing treatment options. Although this may influence elements in decision-making, clinicians should not make assumptions about religious or cultural expectations in a palliative approach.

## **Implications for advanced practice/clinical implications**

According to the American Academy of Nurse Practitioners (AANP), assessment and diagnosis by the Advanced Practice Nurse (APN) is a standard of care for managing patients. The ANP roles are to provide direct expert clinical practice, guidance and coaching to patients, families, and other care providers, consultation, research, clinical, professional, system leadership, collaboration and ethical decision-making. This is the first known study designed to improve the understanding of what it is like living with aortic stenosis as perceived by the participant and to improve understanding of factors that aid in the participant's decision not to have the TAVI. Focusing on client-centered care is closely aligned with core nursing values. The research findings are important in helping health care providers offer treatment options for symptomatic aortic stenosis patients and optimize holistic decision making with patients incorporating the patients' values and goals.

Nursing research, like nursing itself, concerns many different and complex phenomena. By incorporating our knowledge from our learned disciplines, such as biology, philosophy, psychology, with our experience and caring we acknowledge the art of nursing. Florence Nightingale work and writings reflect the concept and philosophy for holistic nursing. Nightingale's legacy is a blueprint practice of observation, inquiry, experience, and nursing art according to Jean Watson (2010).

The data gained from this study provided a deeper insight into the complexity of living life with a long-term illness. Having a richer understanding of the complexity of people making choices for treatment options, advanced practice nurses can provide

guidance to patients and families with ethical decision-making, providing holistic health care that maintains dignity and autonomy. The ANA's Code of Ethics (2014) states the right to autonomy, whereby individuals determine their own treatment choices, is an accepted ethical and legal foundation of healthcare. In the midst of this great change to provide patient-centered care, the nurse practitioners are leaders of the evolving clinical, professional and health care system. Incorporating the knowledge gained from this study, advanced nurse practitioners can improve in their role as patient educators and advocates and optimize collaboration with other health care professionals.

The information gathered in this study will help advance quality and relevance of practice in providing health care decisions tailored to people with aortic stenosis.

Incorporating the patient in research is addressed in multiple venues. In a recent legislative change, The Patient Protection and Affordable Care Act of 2010 created the Patient-Centered Outcomes Research Institute (PCORI). The PCORI recognizes data obtained from qualitative interviews of elicited responses of the patients' experiences' with their conditions and/or treatments promotes value of the patients' voice into the research process (Fleurence et al., 2014). As mentioned by Selby, Beal, & Frank (2012), engaging the patient in clinical effectiveness research emphasizes the importance of patient-centered perspectives when conducting research.

This study identified that some people choose not to pursue procedural or surgical technology when given treatment options for AS. Yet, the trajectory of AS prognosis by medical therapy alone is limited. To provide expert clinical care and honoring the patient's choice of medical modality for treatment, the integration of a palliative

approach in nursing practice is essential to support patients and provide best practice for patients with AS in their last years of life. A new clinical trial being developed, Future Care Planning, is being proposed for patients with advanced heart disease by Denver et al., (2014). It recognizes concerns in providing high quality holistic care by initiating discussion of palliative care. Lauck et al. (2014) introduced a palliative approach to care, focusing on meeting the patient's physical, psychosocial and spiritual needs in life limiting illness such as the AS and TAVI population. Nurse practitioners can provide system leadership by the development and integration of the palliative care team with the University of Vermont Medical Center's TAVI team, to aid clinicians in offering continuity of care when TAVI is not an option.

### **Limitations**

This pilot study provided the PI with an opportunity to share and reflect on patients' experiences and interpretations. There were limitations incurred, namely sample size, style of interview, and length of interviews.

Sample recruitment in obtaining people for this study was challenging. Recruitment was difficult due to the limited number of people in the rural area, the limited number of people who choose not to have the TAVI, and attrition due to the limited longevity of life in this population. This is a very specific population, which narrows the amount of people for sample selection. Hence, a pilot study was adopted, as there were a limited number of patients with symptomatic AS who were not surgical candidates and choose not to have the TAVI procedure. Attrition was also a significant factor as elderly people with AS are a vulnerable cohort. Of the original 75 people,

twenty-five percent have deceased. Cooley et al. (2003) study identified refusal to participate was due to health limitation, lack of interest, and inconvenience and attrition due to death and severity of illness. Fisher et al. addressed the difficulty in recruitment of people when conducting research with end-of-life populations in their study (2012). Recruitment might be more successful if patients were informed of the study during their workup when the relevance of the study is most obvious (Fisher et al., 2012; Sharp, 2010). The introduction of this study by the TAVI team at the time of consultation might possibly have provided more effective recruitment.

Another limitation was the style of interviews. The original study design was to be done using personal interviews in the participants' homes. As the four participants were reluctant to have the PI into their home, the alternative interview occurred using the telephone. This method limited researcher observation with personal contact of the participants' gestures, expressions, and environmental setting.

Lastly, the length of interviews was short. Researchers must consider the varying characteristics and challenges inherent in this cohort prior to initiating further study. According to Fisher et al., (2012) understanding the dynamics and variances among cohorts is key to conducting research.

A distinguishing feature of pilot studies is that the number of participants may be small but they provide rich experiences of unique situations. It is important to realize the quality of responses from each participant, as it is the individual patients' value on their decision-making process. Epistemology includes the view that the truth varies and is subjective. Using a pilot study according to Stanly (2010) offers the opportunity for the

researcher to test the research question, assess the relevance and suitability of the test, and gather preliminary data for future research. Although this study was small, inclusive of only four participants, the strength of the study comes from gathering evidence from the participants directly. While the participants provided rich information for the purposes of this study, there is insufficient material to derive themes regarding generalizability of the findings.

Historically, qualitative research can be dismissed as results and findings obtained can lack validity and reliability. Although using a qualitative discipline, dealing with the complexity of personal reported symptoms, yields ideas that emerge in a wider social context.

### **Discussion of future research/study to pursue**

Research related to what it is like living with AS and reasons not to pursue the TAVI with patients who have aortic stenosis has numerous potential benefits for people, such as sharing their stories, reflecting on their experiences and choices, and contributing to research. This pilot study has generated important new information and points to the need for further research with larger scale studies to explore issues raised in a wider population. Further research is needed in patients with long-term illness and decision-making. Addressed in this section is utilization of different research methods, increasing the geographic area and length of time of study, and expanding on knowledge obtained from this study to gain a broader understanding of what is involved in decision-making in this cohort.

The small sample size potentially omits other perspectives that may be important,

so future research might use a cross sectional design to increase the number of participants. Future study could include three or four adjoining states to Vermont over a period of two to three years. Using a cross sectional method with expansion of the geographic area and lengthening the duration of study, might improve the number of participants and enhance diversity, as Vermont is a small rural area.

Although this study had limited participants, the participants marginalized symptoms of shortness of breath and qualified QoL as relatively good. Further research might be a comparison of people who choose not to have a TAVI who described their symptoms of shortness of breath as insignificant to people with AS who pursued interventions as shortness of breath is the primary contributing issue that patients seek treatment recognized in literature. Is this acceptance or adaptation? Another research study with this cohort could be to review the participant's QoL life assessment measures and note if the participants in this study had a higher QoL score than others who choose to have the TAVI. Having supported data would enhance the qualitative findings.

This pilot study has identified important concepts for shared decision making of treatment options for future research with larger-scale studies within this population that may be transferable to a wider population.

## **Conclusion**

Since the initial TAVI procedure in 2011, there have not been any published studies on individuals' decisions not to pursue having the TAVI procedure. Most studies reported an improvement of quality of life using quantitative measures, but do not focus

on the individuals' ethos on end-of-life options. The patients' perspective and role in this process remain largely unexplored.

Hopefully the information gathered in this study will help advance quality and relevance when providing health care decisions tailored to people with aortic stenosis who choose medical treatment. The study hopes to aid clinicians design interventions aimed at continuity of care when TAVI is not an option. The findings in this study may be important in helping to provide a better understanding of the influences on the decision making process, the need for further research in the area for patients deciding not to have the TAVI, and to encourage nurses to include palliative care options with conservative management.

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## Appendix A

Hello Mr./Mrs./Ms. \_\_\_\_\_,

I am Barbara Worgan, the Nurse Practitioner working with Dr. Dauerman on the Transcatheter Aortic Valve Implantation (TAVI) team at Fletcher Allen Health Care. You met with Dr. Dauerman on (date) to discuss the possibility of having the TAVI and decided that you did not want to have the procedure at that time.

I am wondering if you would be interested in taking part in a research study on living with Aortic Stenosis being done by a Graduate Nurse student at the University of Vermont. Her name is Gayle Hagen-Peter. She has been a nurse for thirty-two years and has returned to school to obtain a Masters of Science Degree as an Adult Nurse Practitioner. This research is an opportunity to help practitioners understand what it is like living with Aortic Stenosis and what factors was part of your decision not to have the TAVI.

If you are NOT interested in being part of this research process, you may contact me, Barbara Worgan, at 802-847-4600. Otherwise, Gayle Hagen-Peter, the Principal Investigator of this research, will contact you by telephone in 7-10 days to see if you would like to learn more and/or participate in this research study. I also am including a research information letter that provides more detail.

If you have any questions about this study, you may contact me, Gayle Hagen-Peter at 802-847-5589 or at 802-578-9809.

Thank you for your consideration in participating in this exciting research,

Barbara Worgan MS, ANP

Gayle Hagen-Peter RN, BSN

## Appendix B

### Research Informational Sheet

**Title Of Research Project:** Living with Aortic Stenosis: a phenomenological study of patients' experiences and subsequent health choices

You are being invited to take part in this research study because you have aortic stenosis and decided not to have the Transcatheter Aortic Valve Implantation (TAVI) with Fletcher Allen's Health Care TAVI team. Please ask any questions you may have before agreeing to be in the study.

Why Is This Research Study Being Conducted? The purpose of this study is to gain insight into the experience of the person who lives with aortic stenosis and what factors into the person's decision not to have medical intervention.

How Many People Will Take Part In The Study? We anticipate approximately 6 individuals will take part in this study.

What Is Involved In The Study? You are being asked to take part in an interview lasting one hour at your home or another convenient location. The questions included will be: What is it like living with Aortic Stenosis and tell me about your decision not to have the TAVI procedure. The interview will be audio recorded for transcription purposes only. Limited private medical information regarding your study eligibility will be added to your research record.

What Are The Discomforts or Risks Of The Study? Although potential risks of this study are minimal, the conversation in deciding not to have the TAVI procedure might cause you to have thoughts and feelings that make you uncomfortable as you reflect upon your decision. If you become distressed you can raise your hand to speak with the researcher, you can take a break or discontinue the interview. Fletcher Allen Health Care's Patient and Family Advocacy phone number is 802-847-3500 and Case Management and Social Work number is 802-847-3553 for community and counseling resources if you feel you need their services.

There is a risk that confidential information might accidentally be disclosed. Professional standards for protecting confidential information will be used to minimize this risk.

What Are The Benefits Of Participating In The Study?

There may be no direct benefit to you for your participation. However, others may benefit in the future by improving understanding of Nurses Practitioners to help communicate and involve patients and their family to actively participate in health care decisions.

What Other Options Are There? Your participation is voluntary and you may refuse to participate or withdraw at any time without penalty or prejudice. If you choose to do so, your information will be eliminated from the study data and no longer be accessible by the researcher or anyone else.

Are There Any Costs? There is no cost to you other than your time.

What Are The Compensation? There is no monetary or material compensation.

What About Confidentiality? All information and audio recording will be kept in a locked file at researcher's home. No names will be used and all data will be coded. Only the researcher will listen to the tapes. The tapes will be kept on a secured computer network and are accessible with a password only known by the researcher. Names of the participants will be coded and a master list to link the identity of the participant will be kept on a private network with passcode access known only by the researcher. The results of this study will be used for publication, but your confidentiality will be maintained. Upon request representatives of the University of Vermont Institutional Review Board will be granted direct access to your research record for verification of research procedures and/or data.

Contact Information You may contact Gayle Hagen-Peter, the researcher in charge of this study, at 802-578-9809 for more information about this study. If you have any questions about your rights as a participant in a research project you should contact, Nancy Stalaker, the Director of the Research Protections Office, at the University of Vermont at 802-650-5040.

Statement of Consent You have been given a summary of this research study. Your participation is voluntary, and you may refuse to participate without penalty or discrimination. By completing the interview, you are agreeing to participate in this study. Your verbal permission to take part in this study will be documented in the research record.

Name of Principal Investigator: Gayle Hagen-Peter  
Address: University of Vermont, Burlington, VT. 05405  
Telephone Number: 802-578-9809

Name of Faculty Sponsor: Sarah Abrams, Ph.D.  
Address: University of Vermont, Burlington, VT. 05405  
Telephone Number: 802-656-3858

## Appendix C

*The University of Vermont*

Committees on Human Research

Serving the University of Vermont and  
The University of Vermont Medical Center Inc.

### **Consent Form Update**

Effective Wednesday, November 12, 2014, our affiliated hospital, Fletcher Allen Health Care, Inc., officially became “The University of Vermont Medical Center Inc.” In consent forms, please substitute all references to Fletcher Allen Health Care or FAHC with The University Medical Center or UVM Medical Center. This is only a change in their name. There are no changes to study procedures, risks or benefits. This change was made to more clearly reflect the academic core and their position as one of the nation’s most respected academic medical centers, and to proudly demonstrate their strong ties to the University of Vermont.

### **RESEARCH PROTECTIONS OFFICE**

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