

**INVOLKING SILVERN VOICES IN HEALTHCARE:  
TRANSFORMING PRACTICE BY ENGAGING OLDER ADULTS IN  
COLLABORATIVE PARTNERSHIPS**

by

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The only source of knowledge is experience.

Albert Einstein

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## Executive Summary

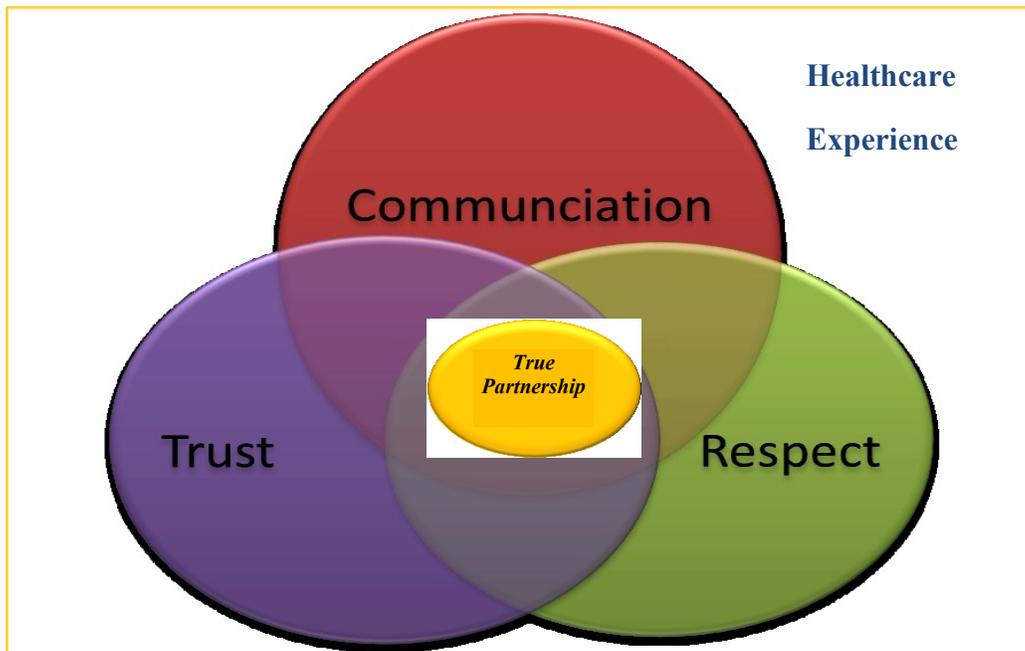
Canada's population is aging. From 1971 to 2012, the proportion of older adults in the population grew from eight percent to fourteen percent (Milan, 2011). This growing trend will ultimately have an impact on nursing practice as older individuals continue to seek healthcare services. Nurses must be able to work in collaboration with the older population to provide quality care.

In healthcare today, individuals are expected to be participants in their own care. As nursing practice continues to be more inclusive of patients in their care, it is important that we fully understand the perspectives of older individuals to become more active participants. It is essential that nurses gain an understanding of how older individuals perceive their participation in their care so we can encourage and support their involvement in healthcare decisions.

Action research is an appropriate form of inquiry to elicit perspectives on participation in healthcare as this methodology requires both parties being active participants in the study. This action research study explored participative healthcare from an older adult's perspective. Thirteen older adults, ranging from sixty-six to seventy-seven years of age, participated in this study to share their healthcare experiences, thoughts and advice using semi-structured interviews to provide an enhanced understanding of the participative healthcare experience.

A simple editing analysis style was used by the clinician-investigator to read through the older adult responses and experiences to identify key words and shared patterns of meaning. This study revealed that older adults prefer to be active participants in their care. The major theme that emerged in analysis was *true partnership*. True partnership means that older adults expect that they work with healthcare professionals as equal partners with a shared care goal to support their health. Three sub-themes that emerged were communication, respect, and trust. These three

sub-themes work in unity to contribute to a healthcare experience that exemplifies true partnerships. This study proposes a definition of true partnership as being open to and inviting mutual communication in an atmosphere that encourages equity sharing of information contributing to respect and the development of trust that results in confident collaboration in care.



“Population aging in Canada is expected to accelerate between 2011 and 2031, as all people in the large cohort of baby boomers reach their senior years” (Milan, 2011). With this growing trend, it is important for nurses to gain an enhanced understanding of health issues concerning the older adult population. Participative healthcare is an important component of care for all people, including older individuals who live in a community setting. It contributes to improved health outcomes and it is vital that healthcare professionals (especially nurses) have an understanding of participative healthcare from an older adult perspective, as nurses often work alongside them in their healthcare. The knowledge and experiences that older individuals shared

in this action research study will provide insight into participative healthcare and make a valuable contribution to current nursing literature.

**Keywords:** Participation, older adults, healthcare involvement, collaboration, partnership

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### **Faith Richardson and Deborah Gibson**

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in this study (and me) acknowledge great respect for physicians who are valuable and vital members of the healthcare team.

## **Chapter One: Introduction and Background**

Canada's population is aging. From 1971 to 2012, the proportion of older adults in the population grew from eight percent to fourteen percent (Statistics Canada, 2011). This growing trend will ultimately have an impact on nursing practice. As older individuals continue to seek healthcare services, nurses must be able to work in collaboration with the older population to provide quality care. To do this, nurses must have access to resources that encourage active involvement of the older adults in healthcare. Older adults' perspectives on healthcare involvement can serve as a foundation for a new approach to nursing interaction by providing a voice to help shape the future of nursing.

In healthcare today, it is an expectation that all individuals will be active participants in their care. Older adults, as the major consumers of healthcare, are especially encouraged to be more active in their care (Lyttle & Ryan, 2010). Patient participation in clinical decision-making leads to improved patient satisfaction with care (Johansson et al., 2002) and is identified as an important indicator of quality nursing care (Kunaviktikul et al., 2005) contributing to a more meaningful healthcare encounter. Both the older client and the healthcare professional must be involved in all aspects of care, including the sharing of information and the decision-making process. The mutual sharing of each unique perspective will contribute to a meaningful healthcare encounter that is beneficial to both the older adult and the healthcare professional. Considering the aging population trend and the importance of participative healthcare, it is vital that we explore participative health from an older adult perspective.

### **Background**

The history of healthcare has traditionally been cast in a paternalistic light. Patients sought medical advice from healthcare providers, mainly physicians, because they were the

experts in health. Assumptions that doctor (or nurse) knew best and made healthcare decisions on behalf of the people whom they were providing care for without seeking their patient's input was the norm (Coulter, 1999). Patients were often seen as passive recipients of care (Hospital Peer Review, 2009) where physicians often provided details of health concerns and notified patients of subsequent treatment plans. However, this paternalistic view was not to continue. The Declaration of Alma-Ata (World Health Organization [WHO] & United Nations International Children's Emergency Fund [UNICEF], 1978) emphasized that health, or well-being, was a fundamental right and emphasized the individual's involvement in healthcare. With this new approach in mind, the definition of primary healthcare (PHC) was adopted as "essential healthcare based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation" (WHO & UNICEF, 1978, p. 7).

As healthcare evolved, the paternalistic model of physician control was transformed into a more inclusive model that evolved into the more recent trend that patients can, and indeed should, be more involved in their care (Picker Institute, 2005). In 2005, the Canadian Nurses Association (CNA) adopted a position that public participation was vital to healthcare, stating individuals and communities have the right and responsibility to be active partners in decision-making about their healthcare and the health of their communities (CNA, 2005). The involvement of patients in their healthcare has been embraced particularly by nursing because it fits well with the profession's beliefs and values about how to care for people (Gottlieb & Feeley, 2006). For the past 20 years, the CNA has advocated for a healthcare system based on the principles of the PHC approach (CNA, 2005). This philosophy, emphasizing client involvement, remains a hallmark for the nursing profession today. As nursing practice continues

to be committed to a client-centered and inclusive approach to care, it is important to fully understand the perspectives of older individuals on active participation.

Healthcare is a dynamic environment. Responding to the advances in practice to enhance quality care is necessary. Nurses have a responsibility to influence change by attending to history, current trends, and future projections in healthcare (Kozier, Erb, Berman, et al., 2014). Nurses must be aware of the roots of practice that led to a paternalistic method of care delivery so that they can critically examine today's practice and philosophy of primary health care, so as to positively influence tomorrow's direction for inclusive service provision. With the expectation of client involvement in healthcare, it is necessary for healthcare professionals, including nurses, to develop an enhanced understanding of care that emphasizes collaboration, rather than assume that quality care can be 'done to' patients instead of 'with' patient-participants.

### **Challenges of Participative Healthcare**

Clearly, patient participation has been recognized as a key component of the framework to guide community nursing practice (Community Health Nurses Association of Canada [CHNAC], 2003) and remains a hallmark for current nursing practice within the community setting. Although participation remains an important factor in elder care, there exist many challenges surrounding the concept of participation.

There have been many terms to describe participative healthcare, such as citizen involvement, consumer participation, active patient participation, partnership-in-care, and collaborative care. Along with the many terms used to describe participative healthcare, there are many definitions used to describe its meaning.

For example, Eldh, Ekman, and Ehnfors (2010) suggest that patient participation is comprised of shared aims and desires between those interacting (the patient and healthcare

professional), calling for a common understanding and mutual respect for each other's contribution. Wellard, Lillbridge, Beanland, and Lewis (2003) find that consumer participation implies involvement of consumers in sharing information, opinion, and decision-making. In an earlier study, Eldh, Ehnfors, and Ekman find patient participation refers to being listened to and regarded as a resourceful individual whose knowledge is recognized and supported (2006). The many facets of this concept highlight the complexity surrounding participative healthcare and emphasize the need to clarify the concept.

There exist many nursing philosophies and theories that emphasize the value of older adult involvement such as positive aging, person-centered care, and family-centered care. In the patient-centered model, individuals are well-informed of their healthcare options and empowered to make autonomous decisions (Doss, DePascal, & Hadley, 2011). Van de Bovenkamp, Trappenburg, and Grit (2009) summarize, "one of the aspects of patient-centered care on the individual level is the expectation that patients become a partner of healthcare professionals, rather than finding themselves in a paternalistic relationship with them. (p. 74)" However, older people report that they do not always find themselves at the center of care (Webster et al., 2005). Nurses often report many challenges with care provision. Factors such as workload, shiftwork, methods of organizing and delivering nursing care, and routinized nursing tasks may singly, or in combination, affect partnerships between nurses and clients (Gallant, Beaulieu, & Carnevale, 2002). Focusing on tasks that need to be accomplished often precedes the nursing care of the client as person. Day to-day provision of patient-centered care is complex and the challenges of providing it, particularly for vulnerable older people in the community, should not be underestimated (Webster et al., 2005).

Registered nurses are in a pivotal position to identify, facilitate, and support patients for participation in clinical decision-making (Florin, Ehrenberg, & Ehnfors, 2008). Engaging older adults in participative healthcare is an important step to supporting their health. It is vital that nurses involved in providing healthcare for the older population understand elder perspectives to the meaning of participation in healthcare. This insight would provide a clearer understanding, which is fundamental in nursing practice to encourage and support involvement. Accessing such knowledge could enhance the registered nurses' (RN) possibilities to use a patient's preference for participation in clinical decision-making and tailor-individualized nursing care. This simple, but profound action is presumed to have a positive effect on the overall quality of healthcare (Florin, Ehrenberg, & Ehnfors, 2008).

### **Definition of Terms**

There are a myriad of healthcare concepts that elicit various meanings to practitioners and clients and can be a source for confusion and misunderstanding. Consequently, to understand and communicate effectively in healthcare, concepts must be defined based on a common understanding of the healthcare phenomena (Meleis, 2005). To help clarify meanings of definitions discussed in this paper, accepted descriptions of the major terms of participative healthcare, partnership, and older population will be explained to assist in the understanding of the perspectives offered throughout.

Today in the healthcare field, individuals are expected to be involved in their own healthcare decisions. A healthcare encounter may involve several (if not all) members of the healthcare team, including physicians, nurses, and clients. With the possibility of many individuals working together with unique backgrounds, it is understandable that there exists

differing perspectives on participation and expected level of involvement. It is important to establish the concept of participative healthcare as a reference for this project.

As this study seeks to find older persons' views on participation in healthcare, it is essential that we understand the inherent need for respect and value of the older adult. Gottlieb and Feeley (2006) understand this need and view this partnership as a collaborative process, defining participative healthcare as a type of nurse-person relationship that emphasizes the pursuit of mutually agreed upon, person-centered goals through a dynamic process that requires the active participation and agreement of all parties. This definition of participative healthcare was adopted during this study. The terms that refer to participative healthcare and are utilized in this study include active participation, active involvement, collaboration, partnership, participation in care, and healthcare involvement.

While it is essential to define participative healthcare, it is also necessary to define partnership, as it is a subcategory of participation. Partnership as defined in nursing literature often is vague. Many authors find it difficult to give partnership a simple definition and go on to list specific qualities or attributes that exist in its presence (Hook, 2006). For example, in Chapman's (1977) *Roget's International Thesaurus*, partnership has been suggested to be associated with affiliation, association, companionship, company, and participation (Lee, 1999).

This paper focuses on the concept of 'partnership' within the context of the relationship between healthcare providers and individuals. Partnership in this context can be defined as a relationship between individuals or groups that is characterized by mutual cooperation and responsibility for the achievement of a specified goal (American Heritage Dictionary, 2006). While the concept of partnership can vary, this is an accepted definition in respected journal articles on partnership in care (Lee, 1999; Wiggins, 2008) and will be adopted here.

The major purpose of this study was to gain an enhanced understanding of participation in healthcare from an older adult perspective. The term “older adult” requires some definition, as the older population can represent variability of age. Globally, the number of persons who are aging is increasing as nearly all countries are undergoing a demographic transition with an increased number of persons aged sixty-five and older (Kleinpell & Kannusamy, 2010). Wetzels, Harmen, Van Weel, Grol, and Wensing (2007) reported that most developed countries have accepted the chronological age of sixty-five years and above as a definition of an older person and this study has adopted that definition. The terms older person/older individual/elder/older adult/older people/older population were used to describe those individuals as being sixty-five years of age and over and are used interchangeably.

As a concept is the basic building block of theory, it is important to ensure professionals (and clients) ascribe the same meaning to a concept (Lee, 1999). Having a consensual understanding of the terms participative healthcare, partnership, and older adult population can provide clarity to promote perspectives discussed in the chapters ahead.

### **Project Purpose**

**Professional.** The purpose of this study project was to gain an enhanced understanding of participation in healthcare from the older adult perspective and to communicate this understanding to make a valuable contribution to existing nursing literature and to improve nursing practice for the older adult population.

Healthcare will continue to be impacted by Canada’s aging population, with older adults being the highest users of the healthcare system (Christensen, Doblhammer, Rau, & Vauperl, 2009). This continuing trend will impact the healthcare system and how we offer services to the older population. With healthcare moving from a traditionally prescriptive model to being more

person-centered and individually focused, it is essential that nurses gain an understanding of how older individuals perceive their participation in care so we can encourage and support their involvement with healthcare decisions.

Nurses, as one of the key providers of care for older people, are well positioned to advance the involvement of older people in all aspects of their care (Cook & Klein, 2005). The nursing role encompasses the coordination of client care plans which are often complex, involving several aspects of care, including a full nursing assessment, the physician's treatment plan, and the client's goal of care. Encouraging and supporting active involvement by the client and advocating for client participation with other healthcare disciplines provides the opportunity for the older adult to have a say in care provision, contributing to an improved healthcare experience.

Nurses must work collaboratively with all experts of the healthcare team to ensure multiple components of care are effectively incorporated into the overall care plan, which is more meaningful to the client (Wiggins, 2008). Gaining an increased understanding of the older adult's expectation with involvement in healthcare decisions can empower nurses to be advocates for greater collaboration with client-physician interactions, resulting in a more meaningful healthcare encounter.

**Personal.** In carrying out this action research study, I was seeking to improve my nursing practice for the older adult population and contribute to an enhanced understanding of healthcare participation to the nursing literature.

Every day, I try to act according to my personal belief that everyone is special and should be respected for who they are with their individual needs and wishes heard. This personal philosophy has influenced my professional life as a nurse. My professional values are that people

should be respected and care should be individualized, centering on individual needs and wishes. This professional philosophy is reflected by the Canadian Nurses Association (CNA) Nurses Code of Ethics (2008); the nurse must recognize and respect the intrinsic worth of a person. As I strive to attain this value in practice, it has also led me to question: am I doing the best I can for my clients? In action research, criteria are set in terms of values that inform practice and are based on certain principles: the need for justice and democracy and the right of all to speak and be heard (McNiff, 2002). This marries well with both my personal and professional philosophies of respect and the right to be listened to. My belief that supporting clients in a respectful manner contributes to a more meaningful healthcare encounter, especially for older people, has led me to explore participative healthcare from an older persons' perspective. Involvement in health and care decisions can improve a person's satisfaction with healthcare experiences as well as increase care quality (Attree, 2010).

### **Project Method**

Action research was chosen as the project methodology as it is a form of inquiry where there is a collaborative, democratic process and active participation by those who experience the situation (Williamson, Bellman, & Webster, 2012). This provides a voice to older adults who wish to share their healthcare experiences to enhance future nursing practice. As well, this two-way approach provides a means to transform practice of the researcher, known as the clinician-investigator.

Patient participation in clinical decision-making leads to improved patient satisfaction with care (Johansson et al., 2002) and is identified as an important indicator of quality nursing care (Kunaviktikul et al., 2005) contributing to a more meaningful healthcare encounter. Therefore, it is important to gain an understanding of what participation in healthcare may look

like for the older population. In order to provide mutual understanding of older adult contribution in healthcare interactions, descriptions of those who have personal experience of the phenomenon should be included, i.e., the voice of patients should be embraced (Eldh, Ekman, & Ehnfors, 2010). Action research provides a method for using the interpretivist paradigm, which emphasizes how humans construct their own interpretation of life (Williamson, Bellman, & Webster, 2012) and was an ideal process to explore older adults' perspectives on healthcare involvement.

This inductive approach was used to gain an enlightened understanding of participative healthcare by gathering and analyzing data to find meaning from older adults' experiences. "The systematic process of inquiry available through action research extends the professional capacities of health practitioners, providing methods that will improve the effectiveness of interventions and augment professional practice in ways that enhance outcomes for clients" (Stinger & Genat, 2004, p. 169). Valuing the knowledge and experience that the older population possess can strengthen nursing practice and contribute to quality care.

To further strengthen this research, the Stringer and Genat (2004) action sequence model was utilized as a guide for this study. It provided a detailed description of the types of activity the clinician-investigator engaged in to systematically investigate practical issues related to practice. The five steps include:

1. research design,
2. data gathering,
3. data analysis,
4. communication, and
5. action

The first two steps are discussed in detail in Chapter Three. Data analysis is discussed in Chapter Four, and communication and action are reviewed in Chapter Five.

Healthcare literature suggests that older people are not as involved in their care as they would like to be (Attree, 2010). This disconnect from our progressing health system to be more inclusive can be a detrimental to the older adult society. It is important to listen to older individual voices so we can gain a broader understanding of the expectations of their involvement to positively benefit their healthcare experiences. To motivate and give the opportunity to older people to take a more active role, if they are able to do so and want so, might help to improve healthcare for this group (Raposo et al., 2005). Action research has been quite recently adopted by healthcare professionals seeking to develop aspects of their practice (Williamson, Bellman, & Webster, 2012) and has provided a respected research method to explore older adult's involvement in their care.

### **Project Aims**

The goal of most qualitative studies is to develop a rich understanding of a phenomenon as it exists in the real world (Polit & Beck, 2008). Once the purpose of this action research study was defined, it was necessary to define focus areas that might enlighten the understanding of the older adult's involvement in care. Initially, the clinician-investigator sought to focus the project by reflecting on values, beliefs, patient care issues, and healthcare literature (Williamson, Bellman, & Webster, 2012). Personal and professional views of individual respect, the interest in current nursing practice on participation, and limited literature on older adult healthcare involvement provided an introductory direction of inquiry to gain valuable insight into older adult's healthcare involvement.

A preliminary list of project aims for this study included:

- to understand the older adult preference regarding their involvement in healthcare decisions,
- to learn from older adults supports that impact their involvement in healthcare,
- to understand how older adults wish to be more involved in their own healthcare,
- to identify factors that encourage/discourage the older adults involvement in healthcare,
- to identify characteristics and behaviors by nurses that older adults perceive as enhancing collaboration in healthcare,
- to identify what characteristics and behaviors older adults possess to be actively involved in their own care,
- to learn from older adults how they experience participation in their healthcare, and
- to communicate these experiential stories to provide a valuable contribution to current nursing literature.

Action research values collaboration and inclusiveness between practitioner and the people they serve (Williamson, Bellman, & Webster, 2012), inviting participants to become co-researchers. After discussions with participants, project aims evolved to focus on the following:

- to understand the older adult preference regarding their involvement in healthcare decisions,
- to identify factors that encourage/discourage the older adults involvement in healthcare,
- to identify characteristics and behaviors by nurses that older adults perceive as enhancing collaboration in healthcare, and

- to identify what characteristics and behaviors older adults possess to be actively involved in their own care.

Action research can enable new knowledge to be uncovered about situations where little or nothing had been known (Williamson, Bellman, & Webster, 2012). Exploring relevant topics that impact client involvement can provide valuable information to nursing practice. The above modified project aims became the focus of data collection and analysis, contributing to an enhanced understanding of older adult's participation in healthcare.

### **Relevance**

“As of July 1, 2010, 4,819,600 seniors aged 65 years and over accounted for 14.1% of the Canadian population...” (Millan, 2011). As Canada's population is aging, it becomes essential to gain perspectives on healthcare issues for older people in order to provide care in a context that they understand and expect.

In healthcare today, people are expected to be participants in their own care. Although participation has been increasingly embedded within healthcare policy, services have had limited success in achieving this (Lyttle & Ryan, 2010), with care providers boasting inclusiveness and the nursing profession embracing participation as a critical aspect of care; why is this? Several reasons may include varying definitions, limited literature, and lack of the older person's perspective on involvement.

The concept of patient participation has been identified in research literature with a range of definitions and perspectives. In most cases, there is a knowledge gap between healthcare professionals and the patients in relation to decisions about aspects of healthcare (Lyttle & Ryan, 2010). A previous concept analysis supports participation as related to aspects of decision-

making, yet the literature base of the analysis primarily mirrors health professional experiences of patient participation (Eldh, Ekman, & Ehnfors, 2010).

The profession of nursing emulates a client-centered paradigm, advocating for patient involvement, but there is limited research supporting this in practice. Florin, Ehrenberg, and Ehnfors (2008), in their comparative study on participation between nurses and patients, stated that RN's are not always aware of their patients' perspectives and preferences when it comes to participation in clinical decision-making.

One of the difficulties with trying to improve care is that the patient experience is not adequately documented (Sprinks & Waters, 2011). There is a need to explore participation in healthcare from an older person's perspective so that nurses have a heightened awareness to support older adult's involvement. However, the insight into the perspectives of older adults on participative healthcare issues is absent. The older adult population is a diverse group whose lives have been shaped by a variety of experiences and backgrounds. To label all seniors the same would be a disservice to the population. "It is difficult to create a comprehensive portrait that illustrates this diversity." (Government of Alberta, 2010, p.3). The existence of diversity within this population brings forth the notion that there may be many conceptualizations of participation in healthcare. Providing an opportunity for older adults to share their perspectives on healthcare involvement is an important step to gaining insight into participation in care.

### **Significance**

The societal contexts in which nurses' work is constantly changing and it can have significant influence on their practice (CNA, 2008). The nursing culture surrounding older adult care is no exception. As older adults continue to access healthcare services, it is important to provide care that meets their needs. Older adults who work collaboratively with health

professionals experience better health and wellbeing. Research suggests that the provider-client relationship offers benefits for clients, particularly for seniors 65 years of age and over (Gantert, McWilliam, Ward-Griffin, & Allen, 2008). In a study on older adult involvement in care, Raposo et al. (2005) summarized that it is increasingly recognised that active involvement of the patient in his or her consultation with a health professional has positive effects on healthcare experiences. Pipe et al (2005) considered when patients are more satisfied with decision-making they may be more likely to adhere to health promotion behaviors and treatment regimens.

According to Andrews, Manthorpe, and Watson (2004), involving older people in choosing and shaping their services enables them to determine their needs, the care they require to meet these needs, and to set the goals they hope to achieve (Lyttle & Ryan, 2010). Adopting this model for participative healthcare means that older individuals are the driving force behind healthcare access and the services they receive. This is a shift from the physicians being in control of healthcare decisions and directing services patients receive and where they receive them (Sanford, 2011). As healthcare continues to move towards inclusiveness, it is important to highlight the older adults' perspectives on participation to ensure healthcare professionals, including nurses, are providing optimal care to the biggest users of the healthcare system.

### **Population of Focus**

The patient-population of focus for this study is Canadian older adults living in community. As 90% of older adults live in a community setting (Public Health Agency of Canada, 2006) it is necessary to invite their perspective to assist healthcare professionals in general, and nurses in particular to help shape healthcare encounters of the future. As a clinician-investigator, I believed it essential to explore the older adult perspective on involvement in their own healthcare experiences and to unfold each participant's account to determine their needs and

their expectations of healthcare professionals before older adults became passively-reliant on the healthcare system. This study provided the elder population the opportunity to share their view and perspective on healthcare experiences with their primary care physicians, with the hope that an understanding of these perspectives will contribute to enhanced nursing care.

Physicians are a valuable member of the healthcare team as they possess valuable knowledge, experience, and skill relating to healthcare issues and are the gateway into the healthcare system for the majority of independently living Canadians. In the community setting, family doctors are often the first healthcare professional that older adults encounter as the primary resource for their healthcare needs. The physician-client relationship is valued because it can lay the foundation for future encounters and relationships within the healthcare system; the physician-provider can do this by practicing mutual respect, by taking time to understand health problems and explaining treatment options in an empathic environment (Marks et al., 2010). Patient satisfaction has been the focus of some studies of older adults' relationships with health care providers. In a large sample (N = 8,859) of community-dwelling persons age 65 and older at least 90% of survey participants expressed they were satisfied with their physicians (Lee & Kasper, 1998).

The healthcare environment advocates for client inclusiveness. However, Hook's (2006) study revealed a lack of experiential connection between the concept of partnership and the actual delivery of nursing care (p.142). Nurses must continue to ensure we are, in actuality, providing quality care in a context that older adults expect. Therefore it is vital that we modify, revise and/or change the way we deliver care.

Exploring the physician-client relationship within the community care context, understanding how older adults experience participation with their family physician and drawing from their strengths and successes can provide nurses with the information and strategies to enhance our professional practice. This exploration will guide nurses to continually provide care that advocates, encourages and supports participation in care. Whatever nurses do, it may be possible to do it better with a better understanding of patient perceptions (Watson et al., 2002 p. 142). This study seeks to add to that understanding by exploring the relationship that most often begins the healthcare journey for older adults in community—the patient-family doctor connection.

The older person's perspective is the key to changing nursing's current knowledge on participative healthcare. Older adults have valuable knowledge, skills, and experiences that can help shape the future of collaborative nursing practice. This capstone project aims to provide the older individual with a voice to help nurses gain a stronger understanding of participative healthcare from their perspective. Hearing stories of older individuals' healthcare experiences will shape how nurses work in partnership with the older population and encourage the older individual to be the center of their care, contributing to a true person-centered approach in health services. As practice moves from mere information giving and consultation to working in true partnership with older people, the real benefits of participative healthcare will be attained (Cook & Klein, 2005).

### **Healthcare Team**

This study's aim was to explore participative healthcare experiences with older people; thus their relationships with family physicians have been highlighted as the most consistently significant component of the healthcare experience for older adults living in community.

The inter-professional nature of healthcare delivery in Canada is unquestioned. As a part of the healthcare team, doctors and nurses work together to provide effective care for the older population. Community health nurses also provide home care and public health initiatives; however these may be less evident to older adults unless they have had recent interchanges with the public health system. Regardless, the physician and the nurse each play an important and complimentary role in the provision of care (Wiggins, 2008).

In the community setting of this study, the majority of older adults' healthcare experiences involve a family health clinic where doctors and nurses work side by side. In the interest of garnering stories of participation in healthcare, as gateway providers, the older adults' personal physicians became the focus of interview responses by the study participants.

The collaborative approach to care has been embraced, particularly by the nursing profession, because it fits well with nurses' core beliefs and values about how to care for people (Gottlieb & Feeley, 2006). While the physician's focus is on the diagnosis and management of illness, the nurses' focus is on the patient's experience of health and illness, including the adaption or practices to promote health and wellness (Wiggins, 2008). A major role of nursing is to develop, implement, and evaluate a plan of care that is meaningful to the individual client.

Nurses are well-positioned for advocacy and leadership roles facilitating involvement in decision-making (Pipe et al., 2005). As overseers of care who practice with from an ethical code, nurses must advocate for client involvement to ensure the client's needs are being addressed, focusing on encouraging and supporting the older population to have a voice. The Canadian Nurses Association supports this as a component of ethical care in the statement that nurses recognize, respect and promote a person's right to be informed and make decisions (CNA, 2008). The entire healthcare team, with the client at the center of care, can achieve advocacy and

care goals more efficiently and effectively if there is a high degree of collaboration between all members (Wiggins, 2008).

As older adults describe their healthcare encounters, it is essential to include family physicians as they are an integral part of the healthcare team and act as a gateway provider for most clients in the Canadian healthcare system. Exploring older adults' healthcare experiences with their personal physicians provides other healthcare professionals a deeper insight into the concept of collaboration. Participation is the hallmark for current healthcare encounters, particularly in nursing practice as it supports collaboration of all members of the healthcare team including the client.

### **Outline of Paper**

This thesis provides an overview of this action research study in six chapters. Chapter One introduces the topic of participation, explaining the relevant terms used in the paper and outlining the study. Chapter Two explains the literature search and retrieval strategies for the preliminary and secondary literature review. A summary of relevant research studies is provided. Chapter Three discusses research design, including sampling, research procedures, and ethical approaches to this study. It also provides an examination of scientific quality and study limitations. Chapter Four presents study findings, exploring the six main concepts revealed in the analysis. Chapter Five offers a discussion of findings and presents an explanatory model figure. Finally, Chapter Six concludes with a summary of the study with recommendations to enhance nursing practice.

## **Chapter Two: Literature Review**

### **Literature Search**

All research studies require a review of current and applicable literature to enhance the study. This action research study on participative healthcare was no exception. Polit and Beck (2008) state a literature review is a critical summary or research on a topic of interest, often prepared to put a research problem in context. The focus of my topic was on participation in healthcare as experienced by older adults living in the community setting. Most older adults live in the community setting, and the need to adopt healthcare services to meet their expectations is necessary for quality care. As involvement in healthcare is expected, a review of current literature is necessary to assist in the understanding of participation as it exists currently. This chapter will discuss the literature review and the search strategies used to gather relevant information focusing on findings relating to partnership.

### **Search and Retrieval Strategies for Preliminary Literature Review**

A cursory review of the literature may help focus or provide a beginning framework for the study (Creswell, 2003). Undertaking a preliminary literature review provided a current understanding of the concept of participation in healthcare. A database search for existing literature involving healthcare participation was conducted in April 2012 by the clinician-investigator using Medline, Google Scholar, and CINAHL (full text), with restricted dates of 2005 to 2012 to ensure current articles were included. Initially, simple terms serving as keywords were used to search existing literature, including peer-reviewed articles. 'Healthcare participation,' 'patient participation,' and 'client involvement' were paired with the terms 'older person,' 'nurse,' and 'nursing'. The literature search retrieved articles from medicine, nursing, and social sciences backgrounds. A plethora of articles was found. With invested time, articles

were reviewed, eliminating studies that involved only children and adults, alternative living environments such as acute care (coupled with acute episodes, e.g., stroke), and residential settings, as well as articles focused on mental health issues, which excluded most articles.

### **Literature Review**

The initial search explored current articles on the definition and concept of participation, using the keyword ‘patient participation.’ The literature search revealed that patient participation remains a highly complex concept in healthcare. Many research articles testified the lack of clarity around the definition and concept of participation.

**Participation concept.** Two concept analysis papers were found that discussed the concept of participation. Hook (2006) examined the partnership within the context of a professional-patient relationship using Roger’s (2000) evolutionary method of concept analysis. Sixty-two articles that focused on expert opinion, literature reviews, and research reports were reviewed. Findings revealed dimensions of partnership; antecedents, attributes, and consequences were included to clarify the concept of partnership, but a definition. In another study, Sahlsten et al. (2008) investigated the parameters of patient participation using Walker and Avant’s (1995) concept analysis approach. This study described four attributes for participation: an established relationship, surrendering some power by the nurse, shared information and knowledge, and active engagement in intellectual and/or physical activities. However, a clear definition was not established.

**Participation perspective.** Many studies acknowledged that the focus of participation has been from the healthcare professional’s perspective and not from the patients who experience it. Eldh, Ekman, and Ehnfors’ (2006) qualitative study explored patients’ experiences of participation and non-participation with their healthcare experiences. Using questionnaires and

responses of 362 individuals, conditions for participation included knowledge and respect, while a lack of knowledge, a lack of respect, and passiveness constituted non-participation. However, there was a notable lack of research on the competencies of healthcare providers required to facilitate participation. This highlighted the need for healthcare professionals to understand and clarify what constitutes participation from an older adult perspective.

Several studies note that there is a difference between a healthcare professional's definition of participation and the patient's. The main purpose of the study by Eldh, Ekman, and Ehnfors (2010) was to compare patients' definition of participation to healthcare's definition. Patients' descriptions focused on having knowledge, rather than being informed, and on interacting with health professionals, rather than merely partaking in decision-making. The difference in opinion demonstrates the necessity to elicit the older population's expectation concerning involvement in healthcare decisions.

Other studies suggest that there is limited research on the perspective of older people. Ryan and Lyttle (2010) completed a literature review on the factors influencing older adults' participation in care. The study included initiatives, reports, reviews, empirical papers, and editorials on the concept of participation. Seven key themes emerged from the literature: the concept of participation, the need for older people to be involved, autonomy and empowerment, patients' expectations, benefits of participation, factors influencing participation, and precursors to participation, offering a complex ideation of participation. This multifaceted concept signifies the need to provide a voice for seniors to clarify their perspective on participation.

The literature review undertaken to clarify the definition of participation in healthcare demonstrated that there were several aspects of client involvement that needed to be addressed. Articles showed that the understanding of and concept of participation in healthcare is varied.

Journal writings discuss attributes of healthcare involvement but neglect to define the term. Other articles claim the definition of participation primarily mirrors healthcare professionals and not that of individuals who experience it, while other articles suggest that the two perceptions on participation differ. Most importantly, it was noted that there existed a lack of older adults' perceptions on the concept of healthcare. From the complexities discovered while attempting to define participation, it became evident that exploration of participation in healthcare from an older adult perspective was necessary. This will assist in defining the term of participation and clarify aspects of care that are needed to encourage and support patients' involvement in care.

### **Search and Retrieval Strategies for Secondary Literature Review**

Once the participants shared their experiences, aspects of participation in care became evident, and a secondary literature review was conducted. The purpose of reviewing the literature in a qualitative study is to place the findings of the study in the context of what is already known (Speziale & Carpenter, 2007). An advanced search was conducted using PubMed, NurseOne, and, primarily, CINAHL (with full text) to explore areas identified by the participants as necessary to support participation with recent studies. This secondary search began in December 2012 and continued until thesis completion to continually ensure current and relevant articles were included. Another literature retrieval technique used in-text citations to expand relevant article searches, which were subsequently retrieved using the CINAHL database.

Search strategies explored nursing models of care as it exists in nursing practice to demonstrate the importance of client involvement. Keywords used to search practice models included 'nursing models,' 'partnership,' 'care delivery model,' and 'patient-centered care' and remained focused on the application to primarily older adults in the community setting and/or applicable in this context.

**Practice relevance.** Many articles stressed the importance of client involvement as it pertains to nursing practice. Wiggins (2008) described the foundation of care delivery model based on partnership, emphasizing engaging and empowerment of patients which is crucial to a cohesive model of care. McCormack (2004) completed a literature-based exploration of person-centeredness in gerontological nursing. While five models of care were considered, stemming from differing practices, they all were firmly rooted in humanistic traditions, articulating the complexity of person-centered practice. Four concepts were identified that emphasized that the act of caring can maintain autonomy. These studies emphasized the importance of client contribution to improve health outcomes and satisfaction with services.

Recognizing that patient participation is a hallmark for practice, keywords such as ‘client involvement,’ ‘nurse-patient relationship,’ and ‘participation’ paired with ‘nursing,’ ‘nurse,’ ‘older adult,’ ‘client,’ and ‘aging’ were used to explore an enhanced understanding of the relationship that exists between nurses and individuals to encourage participation. This phrase was also paired with aspects of care reported by participants, including, ‘voice,’ ‘involvement,’ ‘relationships,’ ‘healthcare experiences,’ ‘self-determination,’ ‘individualized care,’ ‘share decision-making,’ ‘engagement,’ ‘respect,’ ‘trust,’ and ‘satisfaction.’

**Promoting participation.** Several articles found discussed ways to encourage client involvement using collaboration and communication. Communication is an essential component of nursing care and contributes to quality care. Pipe et al. (2005) investigated demographics and shared decision-making factors that contribute to patient satisfaction. This longitudinal study examined responses from 600 respondents. It was found that with increasing age, patients experience less information exchange with healthcare professionals, leaving the patient at risk for negative healthcare outcomes. Penney and Wellard’s (2007) ethnographic study found that

older people equate participation to being independent and found that difficulty in communicating with the healthcare professional impeded involvement, impacting satisfaction with service provision. These studies provide support that increased participation contributes increased information-sharing as a precedent to quality care.

Client involvement in care decisions begins with relationship-building. Gantert et al. (2008) recognized the need for collaboration. This phenomenological study explored seniors' perspectives on relationship building with healthcare professionals. Strategies for healthcare professionals included understanding the senior perspective and getting to know them (as a person), while clients must demonstrate a willingness to work with care providers and ensure the reciprocal exchange of information. Reciprocity, including balancing knowledge, status, and authority, was a valued component of a relationship that contributed to participation and was referenced in this paper to support study findings.

Search strategy continuation. It is important to note other search strategies that were utilized during this study. Google Chrome™ database was used to become acquainted with the older person demographic. Websites for the Public Health Agency of Canada (PHAC), Statistics Canada, and the Government of Alberta were also visited to gather information. To ensure a thorough literature search, in-text citations were retrieved using the CINAHL database. Previous education material and current nursing educational texts were used to gain an understanding of current trends in nursing practice.

The major purpose for this study was to gain an enhanced understanding of participation from the older adult perspective. A literature search was initially undertaken to provide insight into client involvement as understood today in care delivery. Once data was generated and

themes emerged during analysis, a secondary literature search was conducted to support findings with current and relevant research.

### **Chapter Summary and Conclusion**

The concept of participation in healthcare is complex. Studies often report multifaceted components of care that contribute to the concept of participation, but limited research exists on defining participation within the healthcare context. Challenges that were noted included representation of healthcare professionals' perspectives, the existence of various concepts relating to client involvement, and lastly, a lack of the older population's voice, demonstrating the need to provide a voice for the older population to gain their perspective on participation as they experience it in healthcare.

The secondary review emphasized the importance of client involvement in healthcare decisions to improve health outcomes contributing to quality care. A collaborative care approach highlighting communication is essential in care provision. The literature review substantiated the need to elicit voice from the older population to enlighten healthcare's understanding of participation to support quality healthcare. This action research study will provide the opportunity to have a voice to shape future healthcare delivery, making this a valuable contribution to current nursing literature.

### **Chapter Three: Research Design, Method, and Procedures**

Qualitative research seeks to understand the human experience as it is lived, exploring real life experiences of people with first-hand knowledge of the phenomena (Polit & Beck, 2008). My area of interest was participation in healthcare, which stemmed from a personal encounter that caused me to challenge how I practice and what I could do to improve participation with older clients. It is difficult to change my practice without gaining a heightened understanding of what it means to the people I serve. Action research is a form of qualitative inquiry intended for practitioners to learn more about an issue by asking questions about the conditions that are allowing the situation to be as it is and finding ways of changing the condition (McNiff, 2002). I adopted the action research study to explore the phenomena of participative healthcare from an older adult perspective in a collaborative manner.

#### **Research Design**

The goal of most qualitative research is to develop a rich understanding of a phenomenon as it exists in the real world, since it is constructed by the individuals in the real world (Polit & Beck, 2008). My study provides a voice to older adults who chose to share their experiences to enhance understanding of participative healthcare in order to influence future nursing practice.

#### **Research Sampling**

A convenience sample was utilized for recruitment, and there was a small incentive for participating in this study. If a face-to-face meeting was chosen, refreshments were provided. If a telephone interview was conducted, a \$5.00 Tim Horton's gift card was provided. A handwritten thank you card was given to all participants.

By choosing to recruit using a convenience sample, only interested participants contacted the clinician-investigator, and this helped resolve any perceived inequities related to power

between the researcher and participant. During the informed consent process, participants were fully informed of their right to withdraw at any time. Interviews were conducted in a place of their choosing with the purpose of decreasing feelings of anxiety and pressure related to new surroundings. Typically, participants chose to meet in coffee shops and their place of residence or to conduct the interview via telephone.

### **Research Procedures**

**Recruitment.** Informal word of mouth was utilized to seek potential participants for this action research study. Family, friends and practice colleagues were provided posters (8.5' x 11') to distribute to potentially interested participants. Potential participants were informed of this study by individuals who were aware of my enrollment in a master's program and provided a poster with contact information. Once the potential participants demonstrated interest, they contacted the clinician-investigator directly to support privacy. Full disclosure was provided. Participants were informed of the purpose of the study, the responsibilities of the participants and clinician-investigator, risks and benefits, and their right of refusal. If they agreed, they were sent an information package complete with a poster (Appendix A), a letter (Appendix C), and an informed consent form (Appendix D); they were also provided the list of questions that would be used during the interview (Appendix E). They were encouraged to read the information and complete the consent and return it to the researcher either in person or via mail. A self-addressed, stamped envelope was provided with no financial costs to the participants.

Inclusion criteria were sixty-five years of age and over, living in their own home, and fully able to understand and communicate in English. Exclusion criteria were known or expressed mental deterioration due to disease processes that would interfere with everyday communication and understanding.

**Informed consent.** Consent was both verbal and written. Verbal consent was obtained once they contacted the clinician-investigator who provided full disclosure. After verbal consent was obtained, they completed and returned the written consent form via mail. An additional copy of this form was provided to the participants to keep for their own personal records.

**Semi-structured interviews.** The recorded interview was approximately one hour in duration and was conducted over the phone or face to face. The interview took place either at the participants' home (telephone) or a mutually agreed upon location (face-to-face). The interviews took place between October 19 and December 12, 2012. The recorded interviews averaged 30 minutes in length (range 15 to 50 minutes), with an additional 15 minutes for debriefing, as well as approximately 5 minutes prior to recording to ensure participant understanding and to obtain verbal consent before the recorded interview.

### **Method of Analysis**

The focus of this action research study was to gain an enhanced understanding of older adults' perspective regarding their involvement in their own health care decisions. In order to provide participative healthcare to older adults, it is imperative to enhance our understanding of what participative healthcare is to them.

The purpose of data analysis is to organize, provide structure to, and elicit meaning from research data (Polit & Beck, 2008). Data analysis in action research involves exploring individuals' experiences to generate new knowledge and understanding from participants' stories. A review of the data elicited key words and shared patterns of meaning from the participants' own responses which ensured the data remained genuine. This allowed the clinician-investigator to demonstrate the development of new meaning utilizing the perspectives of the participants to enhance accountability (Williamson, Bellman & Webster, 2012). To better

enhance our understanding of the phenomenon, we will explore participation from the perspective of the older adult utilizing both qualitative and quantitative data.

**Qualitative data.** Qualitative data is collected in narrative form and usually collected via interviews (Polit & Beck, 2008). Qualitative data was obtained through responses to the semi-structured interviews which were transcribed verbatim. A simple editing analysis style was used to identify keywords, concepts, and shared patterns of meaning contributing to the development of subthemes and ultimately an overall theme. The initial six concepts emerged from the questionnaire that explored areas of participation including perceptions, factors that both encourage and discourage involvement as well as characteristics needed by an older adult and healthcare professional that promote participation. See Appendix E for the complete interview questions. Participants' responses to these six concepts of participation were reviewed by the clinician-investigator that revealed the three subthemes of communication, respect and trust leading to the overall theme of true partnership.

**Quantitative data.** Quantitative data refers to data that is collected in numerical form and can provide strength when analyzing qualitative data. Forms of quantitative data for this study included demographic information and pivot tables that graphically manipulate the data. During data analysis, Microsoft EXCEL™ pivot tables were utilized to cross tabulate data to analyze for further patterns of meaning. The topics considered for relationships included: perceived self-health rating with believed healthcare involvement, length of time with family physician perceived ability to communicate with the physician, relationship, perceived ability to communicate with physician with perceived opportunities for participation, perceived self-health rating and perceived opportunities for participation, perceived self-health rating and perceived ability to communicate with the physician, and the stated number of visits to an emergency room

and perceived ability to communicate with the physician. Findings will be discussed in detail in Chapter Four.

## **Ethics**

Nurses recognize that they are moral agents in providing care. This means that they have a responsibility to conduct themselves ethically in what they do and how they interact with persons receiving care (CNA, 2008). This is also true in conducting a research study to enhance nursing practice. This action research study was completed as a requirement of the completion of my Masters of Science in Nursing (MSN) from Trinity Western University (TWU). I obtained Research Ethics Board approval through the TWU ethics committee prior to my study (Research Ethics Board (REB) file number: 13G14. Approval date: October 22, 2012).

**Scholarly Review.** This action research project proposal was approved by my course advisor, Faith Richardson, DNP, and my second reader, Professor Deborah Gibson with the TWU School of Nursing. I continued to work with my committee throughout the project. This project was not funded.

**Scholarly and Clinical Experience.** As part of program completion, I have successfully passed all the Master's program core courses, including Nursing 520: Knowledge Synthesis; Nursing 530: Scholarly Inquiry I (a study in qualitative research methods); and Nursing 540: Scholarly Inquiry II, Knowledge Synthesis. As a component to providing ethical care, nurses support, use, and engage in research and other activities that promote safe, compassionate, and ethical care (CNA, 2008). In preparation for this capstone project, I completed the Tri-Council Policy Tutorial Course on Ethics Research (CORE), located at [www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca), to gain a comprehensive understanding of the ethical principles required for research projects in

preparation for my capstone project. A copy of the certificate of completion can be seen in Appendix B.

In my professional role as a Registered Nurse and nursing practice instructor with University of Calgary, I work with students, nurses, and seniors everyday with an aim to improve practice for nurses and improve health outcomes for the older population. As this was my first involvement with action research, I have chosen a topic that is applicable to my area of practice and has the ability to improve my nursing practice. There is no conflict of interest with my involvement in this study.

**Risks.** The ethical concept of beneficence requires that healthcare providers minimize harm to participants and maximize benefit. For this study, there were no foreseeable risks to participants. To mitigate any risks, participants had the opportunity to not to answer questions and withdraw from the study at any time; they were also provided time if they verbalized anxiety or if signs of distress were observed.

**Benefits.** There were potential benefits to this action research study on participative healthcare for the participants. Indirectly, the information they shared potentially could enhance future nursing care. Direct benefits to participants might result from the affirmation that they are indeed participants in their own care, and this understanding may support and enhance their own participation in their healthcare encounters in the future. The knowledge and experience participants shared contribute to empowered involvement with the nursing profession, potentially impacting nursing care to be more supportive of participation in healthcare.

### **Scientific Quality: Validity and Reliability**

Personal accounts and information-sharing by the participants enhanced my understanding of participation in health care. When exploring perspectives, I considered Lincoln

and Guba's (1985) framework, which is considered the gold standard, to ensure the trustworthiness of my study. It involves credibility, dependability, confirmability, and transferability as approaches to enhance the trustworthiness of my study.

### **Credibility**

Credibility refers to the confidence in truth of the data and interpretations of them (Polit & Beck, 2008). This study involved thirteen older adults' perspectives on their involvement in their healthcare, utilizing semi-structured interviews. The taped interviews, verbatim transcripts by an independent professional, and field notes all were considered as contexts to ensure accuracy of participants' experiences. According to Stringer (1999),

Credibility is established by prolonged engagement with participants, triangulation of information from multiple data sources, member checking procedures that allow participants to check and verify the accuracy of the information recorded; and peer debriefing processes that enable research facilitators to articulate and reflect on research procedures with a colleague. (p. 176)

**Patient Engagement.** Participant contribution is essential to action research methods because it is their unique knowledge and experience that help hone the study direction and provides the basis for the study findings. An action research project in a clinical practice environment requires an understanding of collaboration to design and implement the study (Williamson, Bellman, & Webster, 2012). To encourage a collaborative environment, an attitude of respect and genuine interest was shown for the older person's knowledge and experience, transparency was utilized in providing study information, ethical consent and privacy needs were addressed, and an open and supportive environment was encouraged to provide a climate for participants to disclose their thoughts and experiences without concern. During the study and

afterwards, the participants received contact information of the clinician-investigator and were encouraged to connect anytime to discuss concerns, ideas, thoughts and feelings to ensure continued interest and involvement in the study.

**Triangulation.** Triangulation refers to the use of multiple methods to collect and interpret data about a phenomenon, “so as to converge on an accurate representation on reality” (Polit & Beck, 2008, p. 768). Data sources for this capstone project included literature reviews (discussed in chapter two), researcher field notes (including reflexivity), and semi-structured interviews that were recorded to provide rich text and generate new data and meaning of participation in healthcare from older adults.

**Field Notes.** Field notes were taken by the clinician-investigator to record unstructured observations made in the field and in the interpretation of those observations (Polit & Beck, 2008). Field notes help the researcher to gain an enhanced understanding of what is happening and to gain an understanding of the data as meaning emerges. In addition, field notes can be described as giving accounts of action research studies to add credibility (Parahoo, 2006). My field notes consisted of observational, theoretical, methodological, and personal notes, which added depth to the information collected and remained a separate source of data from participant interviews.

Reflexivity is important in all qualitative studies, especially in action research. It is the constant process of critically reflecting on actions and behaviors relating to the interaction with participants and the research process (Williamson, Bellman, & Webster, 2012). Reflective notes served as a record of my personal experiences, thoughts, and progress while completing the capstone project. I continually recorded my thoughts, feelings, and actions in my field notes to demonstrate background motivations leading to enhanced practice.

It is especially important during any qualitative research study to be cognizant of how the researcher may interfere and influence study findings. Exploration of personal beliefs makes the researcher more aware of potential judgements that can occur during data collection and analysis (Jootun, McGhee, & Marland, 2009). Throughout this action research study, I was aware of my biases and assumptions and made a concrete effort to actively listen to participants' stories and perspectives that were separate from my own. I ensured this through field notes, where my personal thoughts and ideas differentiated from participants' information. This was a form of bracketing, the cognitive process of putting aside one's own beliefs, not making judgements about what one has observed or heard, and remaining open to the data as revealed (Speziale & Carpenter, 2007). This ensured that the participants' experiences were the findings of the study. In Chapter Five, I also describe the learning that has occurred as a result of this research on participative healthcare. As action research defines, it is important to recognize that the meanings of the embodied values become clear in research (McNiff, 2002) which adds authenticity to my action research study.

**Member Checking.** Member checking is crucial to action research to ensure the participants' stories are the genuine source of new knowledge. Once the preliminary one-on-one interviews were completed and data analysis of emerging concepts and ideas was established, an executive summary was provided to the original participants to ensure accurate and complete information had been obtained. This provided the participants an opportunity to express other ideas they perceived as important which were not addressed during the interview or addressed in the summary. A detail of participants' involvement is discussed in Chapter 5 (p. 68).

**Peer Debriefing.** Peer support, including constructive criticism, can also be valuable in helping critical reflection, learning, and development in how new themes, discussions,

arguments, and conclusions are clearly constructed and subsequently presented (Williamson, Bellman, & Webster, 2012). During the process of this action research study, I was assigned an advisor, Faith Richardson, DNP (Doctor of Nursing Practice), who is a professor with Trinity Western University. Dr. Richardson has provided me with guidance while developing a proposal, conducting the interviews, analyzing data, and generating new knowledge and functioned as peer review during thematic analysis.

The very real concern in any qualitative research study is that the story that emerges is the story of the people (Speziale & Carpenter, 2007). Action research is no exception, as it is the participants' lived experience that generates new knowledge. Credibility of action research is an important consideration to demonstrate that findings are the true representation of the individual's lived experience. Utilizing Stringer's (1999) framework of participant engagement, triangulation, including field notes and reflexivity, member checking, and peer debriefing contributed to the credibility this study's findings.

### **Dependability**

Dependability refers to the stability of data over time and conditions (Polit & Beck, 2008). Due to the participants' willingness to share their perspectives and the tenacity to which they hold to their views, I believe that the study findings are repeatable, provided that the same study was to be duplicated with similar participants and context.

### **Confirmability**

Confirmability refers to objectivity that the data does indeed reflect that of the individuals in the study (Polit & Beck, 2008). As the researcher explored differing perspectives, there were no unexpected responses from the participants. Study findings were reflective of the participants'

complied stories, responses to questions, and any further comments that they felt comfortable to share.

### **Transferability**

Transferability refers to the generalizability of data. This study found that older individuals prefer to be involved in their healthcare decisions, with the expectation that they are an equal member of the healthcare team and actively participate in the decision-making process. This finding can be generalized to older adults living independently in a community setting with similar characteristics to this study's participants.

In action research, it is especially important to undertake measures to ensure that the study findings reflect that of the participants. An attitude of collaboration, a commitment to cooperation, and an obligation to democracy and empowerment is essential for action research (Williamson, Bellman, & Webster, 2012). An awareness of the areas of credibility, dependability, confirmability, and transferability during the initial steps of my study and constantly revisiting these throughout the study with conscientious bracketing allowed me to enhance the trustworthiness of my qualitative action research study.

### **Study Limitations**

This action research study explored the perspective of thirteen older adults. The majority of the participants (nine out of thirteen) resided in the province of Newfoundland. This group shares similar contexts and backgrounds. The high representation of this group can be considered as capturing a homogenous voice of this specific older adult aggregate. In one sense, this can be considered a limitation of the study; in another sense it can be seen as strongly capturing a unique group voice, emphasizing this group's expectation to be involved in their healthcare decisions. Participants from other provinces (Alberta and British Columbia) provided a variation

to the study group, however, they also shared that they expect the same level of contribution, strengthening the observed finding that there is a shared expectation among older adults in Canada that they believe they should be highly involved in their healthcare decisions.

Data saturation was achieved; however, the small sample size affects the generalizability of study results. To strengthen generalizability, this study would need to be replicated in other communities within different cultural and ethnic groups. Similarly, the context of healthcare delivery was within the community. This study could be adapted to include participants in residential care and assisted living in order to get a more complete picture from older adults from a wider range of living situations. One of the criteria for inclusion in this study was that participants were to be cognitively intact, which may have influenced responses as older adults with mental challenges may hold differing values and respond differently. As well, most of the participants had post-secondary education, which may have influenced the perspective that was established of expecting involvement in care. Florin, Ehrenberg, and Ehnfors (2008) suggest that participant education level can influence results.

Recruitment for this study was done by sharing study information with family, friends, and colleagues who subsequently shared with other older adults. This resulted in participants contacting the researcher independently. Participants effectively self-selected, which may indicate that these older adults are already more motivated to be involved in care as compared to the larger older adult population. Also, most of the participants related their health status as excellent or good. There is the consideration that these older adults were more likely to initiate active participation in healthcare decisions than counterparts who considered their health to be poor or needing improvement, creating a biased sample. Although this qualitative action research study illuminated health care involvement from an older adult perspective, quantitative methods

with a larger sample size may provide a wider range of views and perspectives contributing to an enhanced understanding of the issue (Lyttle & Ryan, 2010).

A heightened understanding of authentic client-centered care is important for nursing practice. Client involvement is an essential component for this approach. Patient involvement improves satisfaction with services and also improves the appropriateness and outcomes of care (Ellins & Coulter, 2005). While this paper contributed to an enhanced awareness of participative healthcare from an older adult perspective, it is essential that we continue to explore this phenomenon in an effort to provide the quality care that older adults expect. The older adult population consists of unique individuals with differing values, life experiences, and perspectives. While older people as a group may have similar experiences, this does not mean that their needs are identical, and that assumptions should be subsequently made about their care (Reed and McCormack, 2005).

## Chapter Four: Findings

Older adults are the largest consumers of healthcare. With Canada's aging population, this will ultimately have an impact on healthcare services and consequently how nursing care will be provided to this population. Older adults' experiences with healthcare encounters can offer a wealth of information and provide a better understanding of the expectation older adults have from healthcare professionals to support older adult involvement in care.

This chapter explores participant responses relating to the concept of participation. In reviewing the data, it is important to note that participants highly valued their connection to their family doctor. This strong trend of positive responses concerning their family doctor appears to have strongly contributed to their overall satisfaction with their healthcare experience. The study findings and older adults' experiences are presented here for the purpose of seeking to gain a clearer understanding of how this patient group perceives participation in healthcare.

### Participants

**Demographics.** Thirteen participants residing in Canada (primarily in Newfoundland) contacted the clinician-investigator to share experiences of participation in healthcare for this action research study. The age range of participants was sixty-six to seventy-seven years. Participants were English Caucasians who predominantly had a secondary education. A visual representation of the participants' demographic makeup is demonstrated in Table 1 and can be reviewed on page 119.

All the participants in this study exhibited similar demographic similarities, being English-speaking Caucasians with a secondary education. The mean age of participants was 69.9 years, reflecting the initial years of older adulthood. With the majority of respondents being

sixty-five to seventy years of age, study findings may strongly reflect this older population cohort but limit generalizability to other older population age groupings.

**Beliefs and assumptions.** Participants were asked twenty questions about their healthcare experiences with their primary care physician. The first several questions of the interview focused on gathering data about the participant's beliefs concerning their own health and relationship with the healthcare system, including one global question about personal perspective of the importance of having a voice in healthcare decisions.

Quantitative data was also used in this study in the form of pivot tables. Pivot tables were used to further identify shared patterns of meaning by recognizing possible associations in the data to further strengthen findings. The pivot tables were also used to explore participants' self-rated health with perceived healthcare involvement. Table 2 (p. 120) provides a visual representation of participants' responses that allow the clinician-investigator to make connections. The majority of participants (85%) believe themselves to be in excellent or good health with 100% responded that it is very important or important to be involved in healthcare decisions. This positive finding can reflect the strong desire of the healthy older adult population to be involved in their healthcare decisions.

Table 2 (p.120) was also used to explore the relationship with the length of time with family physician with ability to communicate with their physician. All participants (100%) have a family doctor with 85% having the same family physician for more than 3 years. 92% of participants shared that they can easily talk with their family doctor suggesting that a strong relationship with the healthcare professional with the opportunity to communicate can contribute to increased involvement of the older adult in their healthcare decisions strengthening study findings that time is needed to build trust.

## Interview Findings

**Overview of findings.** This study clearly indicated that older adults preferred involvement in healthcare decisions. The major theme that emerged in analysis was *true partnership*. Older adults expect to work with healthcare professionals as equal partners in care with a shared goal to support their health, signifying a true partnership. Three subthemes that emerged were *communication*, *respect*, and *trust*. All three subthemes must work together in unity to contribute to a healthcare experience that originates from true partnership.

During initial analysis, six main concepts emerged, healthcare involvement, supporting participation, older adult participation, factors influencing healthcare involvement, factors that encourage healthcare involvement, and characteristics promoting active participation. Exploration of these concepts guided the understanding of the older person's preference with healthcare involvement and the development of the overarching theme of true partnership.

True partnership necessitates that all members of the healthcare team (including the client) be involved in the decision-making process. Study findings demonstrate the strong desire of the older adult to be an active participant in the care process.

**Healthcare involvement.** One aim of this study was to understand the older adults' preference regarding involvement in their healthcare decisions. Findings from this study show that older adults prefer to be involved in their healthcare decisions. Twelve out of thirteen participants state it is very important to be involved in health care decisions, emphasizing that their input is "critical" (Participant #3). Their strong desire to be involved in healthcare decisions

became evident, as Participant #4 stated, “I certainly would not appreciate it if someone... a physician did not involve me in them.”

When asked to rate the statement “Doctor knows best and a patient’s role is to listen and follow advice,” 61% of respondents answered strongly disagree or disagree, demonstrating their opposition to no involvement. “Well, if I am capable of input, I don’t think that the doctor should... make decisions for me” (Participant #2).

When responding to the question, “Do you feel there are always opportunities for your involvement in health care decisions?” eight responded always. The remaining five participants responded sometimes, often citing emergent situations as being an outlier. “Maybe I wouldn’t be able to have input if I was in an accident” (Participant #9). Responses also suggest that they have to rely on physician’s judgement in times of crisis, “Maybe there are times I would leave it up to the physician who has a much greater understanding [of my emergency situation]” (Participant #4). With this exception to involvement, there is also an expectation that the doctor attempts to make a decision that is in the client’s best interest. Participant #10 explains, “Only in times when unconscious, can’t speak, an accident victim [would I not be involved], but I would have the expectation that they [healthcare professionals] would be speaking with my family or power of attorney.”

This study indicates the tendency of participants to be an active decision maker in their own healthcare decisions. With the exception for emergent situations, involvement in care appears to be an expectation for these older adults: “There really isn’t a time when you should not be involved at all” (Participant #1).

True partnership means that healthcare involvement is the standard of care. For participation to be realized in practice, it must be supported by the healthcare professional, the

family, and the individual themselves. All three must work in together to ensure trust that the older adult's wishes will be carried out at all times.

**Supporting participation in healthcare.** This study indicates that there are many factors that impact older adults' involvement in their care, including relationship with the healthcare professional, family support, health status and the personality of the client.

This study supports the finding that having a consistent care professional assists with patient involvement in healthcare decision-making. All of the participants have a family physician, with eleven of thirteen participants having had the same doctor more than three years. The building of a relationship with the same healthcare provider contributes to a good relationship, as 92% chose the statement "I can easily talk to him/her about my health concerns and feel he/she takes the time to listen." Older individuals develop an understanding of support that contributes to trust in their family doctor and independently decides if the relationship is beneficial. "...I have trust in my physician even though she very young. If I was dealing with [healthcare encounters] I didn't feel was helpful, I would definitely be taking my business elsewhere" (Participant #10). With time, they begin to develop an understanding of one another's perspectives. "She [physician] is extremely thorough, takes a lot of time with us" (Participant #11).

Another area that impacts a clients' involvement is family support. Family can often encourage healthcare discussions and provide direction to choices. "I might run it by him [husband] and sort of together we might decide what we think is best" (Participant #4). Another area where family can support an older adult is to support their wishes. "Of course, they [family] know my wishes and go by that in the will" (Participant #8). This provides reassurance that their

request for healthcare decisions will be carried out in the event they are not able to speak for themselves.

The health status of the older adult may have an impact on involvement. Eleven out of thirteen participants reported their health to be excellent or good. Health status may have a positive impact on participation, as often older adults wish to remain as independent as possible and take measures to support their own health.

The knowledge level and personality of the older adult has a positive influence on their involvement. All participants in this study had completed high school; the majority (n = 10) of them completing some post-secondary education or graduate level studies. All respondents had secured employment in various roles upon retirement. The responses to questions suggest that the higher the education received, the greater the participation. For example, a participant with a post-secondary level of education stated, “I think you need to be aware of what’s happening to you, ask good questions and if you don’t get an answer, ask again” (Participant #7).

Willingness to be a self-advocate also contributes to participation. It would appear that the more confident an older adult is to speak up, the more participation will occur between the provider and patient. Speaking about people who ‘speak up’ during medical appointments, one participant stated, “I think that you have to be knowledgeable. They (seniors) have the ability to give and take, they need to be assertive...they need to be advocates for themselves” (Participant #10). This study’s participants demonstrate that education level and ability to communicate needs and confidence are associated precursors for participation.

True partnership denotes an open environment where both the older adult and healthcare professional have the opportunity to share their perspectives.

**Older adult participation.** This study also explored how older adults wished to be more involved in healthcare decisions. After studying responses, two categories appeared: participants who wanted to be more involved (n = 5) and participants who were happy with their current level of involvement (n = 7). Both these groups connected ‘involvement’ to communication.

Findings indicated that participants who expressed an interest for more involvement in their care suggested communication enhancement focused more on open discussions with their healthcare professional and more initiative on behalf of the older adult to ask questions. First, participants explained that they would like greater information-sharing from the physician. Participant #1 shares her perspective on topics of discussion expected with healthcare practitioners to facilitate the sharing of information, “Open discussions with doctors and other healthcare professionals as to my illness, explanation of same, treatment recommended and any adverse effects of drugs and other treatments [being considered].” Participants expressed a need for a more detailed explanation to feel more knowledgeable about their situation. “They don’t always go over them [lab tests] with me, so I’m not always sure” (Participant #6).

Patient initiation is also a consideration for improved participation. Participants themselves expressed a need to self-advocate. Participant #10 describes the goal of “being comfortable to ask my own questions, [and] being satisfied with the answers I am getting” as reflecting the need to be more assertive and open to sharing information. Participant #6 states, “I think you need to be aware of what’s happening to you, ask good questions and if you don’t get an answer, ask again.” Another area for consideration is motivation to find out about their health status. For example, as participant #13 stated, “You have to gather you own information along with theirs.” This reflects the older adult’s responsibility to be more informed and to ask

questions if they don't understand, "Because a lot of times, [doctors] don't tell you exactly what you are looking for" (Participant #12).

This study indicates that some older adults are satisfied with their current involvement in their health care, suggesting that the opportunity for open discussion is present. This seems to stem from their already well-established mutual relationship they have with their family doctor: "I think I get really good advice from my doctor.... Of course I'll ask him about his decisions and why and so forth" (Participant #9). The satisfaction of involvement relates to having the opportunity for open discussions: "Well, I feel that I am directly involved now, I don't know how it could be any different because I discuss everything with my doctor, so the doctor is right there, she's very open with me and...I ask questions when I don't understand" (Participant #3). Both current satisfaction of involvement and the desire to be more involved relate to open discussions with the health care professional.

Quantitative data was also used in this study in the form of pivot tables. Pivot tables were used to further identify shared patterns of meaning by recognizing possible associations in the data to further strengthen findings.

Pivot tables provided a way to explore possible associations between the concept of perceived ability to communicate with the physician and perceived opportunities for involvement. Table 3 (p. 121) provides a visual representation of participant responses that allows the clinician-investigator to make connections. The majority of participants (92%) feel they can easily talk to their family physician and feel he/she talks the time to listen with 67% of these participants feel there are always opportunities for involvement. None of the participants (0%) chose the response that there were rarely or never opportunities for involvement. This positive association between communication and involvement suggests that communication can

positively influence the older adults' involvement in healthcare decisions providing strength to study findings.

True partnership means that both the older adult and the healthcare professional must respect each other's perspective and demonstrate a willingness to invite an opportunity for discussion.

**Factors influencing healthcare involvement.** From this study, it is evident that a major factor discouraging patient involvement in care is a lack of opportunity for discussion. There are many reasons cited for this including physical condition and unpreparedness. The physical condition of the client may decrease opportunities for open discussions, "I was just complacent in that respect I guess after the pain symptoms" (Participant #3). Unpreparedness is another factor, as participants report they had not had time to prepare for the healthcare news they had received. This is supported by Participant #12, "I don't know why we do that, but, we go blank and when you get home you say, how I didn't ask that question." She continues on by stating, "Maybe I should be more involved in that, you know, at the time, I don't think you stop and think...."

Factors that encourage involvement were also explored. This study found that a major contribution to older adult involvement is respect. Participants in this study reported mutuality to be a key concept for respect. Participant #2 captured this by stating, "Not saying 'this is what you should do,' but giving me options so that I could decide."

True partnership requires an atmosphere of mutuality where the older adult and healthcare professional bring their knowledge and strengths to the relationship, valuing each perspective, contributing to a respectful exchange.

**Factors that encourage collaboration.** Older adults who participated in this study described characteristics and behaviors health care professionals demonstrate to enhance collaboration in healthcare. Communication and respect for a mutual relationship was vital.

Strong communication skills are beneficial to the collaborative relationship. “The biggest thing you can do...for anybody is listen” (Participant #5). Listening provides the opportunity for information exchange and comfort by the older adult. “I did not feel I should hesitate in asking him for advice or questions” (Participant #1).

Terms used by the health care professional in describing health situations often posed a challenge for the older adult to have an understanding of their health status. Many participants commented on using language that is understood by the client. Participant #3 states, “...they [healthcare providers] need to speak so that the average person can understand what you’re talking about.” When common language is used and understood with the client, it enhances understanding, helping to remove this barrier to communication.

Having an understanding of a collaborative relationship for both the client and healthcare professional is vital to enhancing participation. Participant #4 states that physicians must “be respectful of people’s right to participate in their health care.” The healthcare professional must value the older person’s perspective and accept their willingness to participate. The willingness to accept input from older adults contributes to respect for their opinions. Participant #1 shared her view on being involved: “...the only thing that I would say is all seniors would like to be treated as...not as somebody who’s at the end of the road, but people who are still able to communicate and who are interested....”

Participants also acknowledge that they have a role to play in this process. Participant #5 comments, “[older adults] should be taking advice...that’s a part of your own involvement in it

[health care decisions].” The willingness to accept advice enhances a mutual respect for both the healthcare professional and client which enhances participation in decision-making. “She had respect for me and I had respect for her” (Participant #3).

True partnership means that the older adult and the healthcare professional bring their unique perspective to the relationship. If capable, the older adult must be able to speak up by asking questions and communicating their needs, demonstrating their willingness to be involved.

**Characteristics promoting active participation.** When exploring older people’s participation in healthcare decisions, it is important to explore their perspective on characteristics older adults must possess to be involved in their own healthcare. Two attributes emerged, including capacity and willingness to be an active participant.

Capacity appears to be an important factor with regards to involvement. “If you are mentally capable of being involved... [you] should be given the choice and the opportunity” (Participant #7). This is supported by a comment made by Participant #2, “If I am capable of input, I don’t think the doctor should...make decisions for me” signifying their desire to be involved.

A second characteristic in patient motivation is to seek out more information. “In order to be your own expert, you need to know something about it, you know, you’ve got to be informed” (Participant #3). Having the incorrect information can negatively impact participation. The less information they have, the less likely they are to become involved. It appears that an older adult’s self-confidence improves participation. Participant #5 states, “[older people] need to be assertive...they need to know what their problems are...” Participant #10 agrees: “...they (older adults) need to be able to advocate for themselves.”

Participants feel that in order to be informed and able to contribute to healthcare discussions, the older adult must do some information-seeking to be more knowledgeable about their own situation. As Participant #13 stated, "... you have to gather your own information along with theirs...recommendations don't tell you the truth." Older adults understand that they need to be active in seeking out more information for better understanding of their health concern and therefore better able to contribute to discussions. "Ask the Doctor different questions, that we were looking up on the computer...so that we kind of know where we're at and what to discuss and what questions to ask" (Participant #11). Not having the knowledge and motivation to be involved can negatively affect care.

True partnership means being open to and inviting mutual communication in an atmosphere that encourages equitable sharing of information, contributing to respect and the development of trust that results in confident collaboration in care.

### **Stories of Non-participation**

During discussions with participants, other healthcare experiences were shared to help contribute to an augmented understanding of participation in healthcare. When clients were asked if they wished to share any other experiences, an understanding of their view of participation became visible in several stories of what they described as being situations of 'not participating.' These included a paternalistic physician, a lack of communication with the patient and difficulties in language comprehension.

**Paternalistic Physician.** One participant shared a story about a doctor overriding patient wishes with known family members during the final stages of the life of a friend. "The patient wanted no CPR, no resuscitation, ventilator or anything like that. When the time had come, the specialist went to the family members and asked what they wanted when the patient was right

there and lucid. The doctor or healthcare professional is looking at the family members and asking the questions, not the person to help...and, they don't even realize they're doing that" (Participant #7). This corroborates that the actions of the physician of not listening to the client's wishes contributed to a negative healthcare experience.

**Lack of Information Sharing.** Communication is essential for developing trust with the healthcare professional. Participant #2 recalls a healthcare experience where she had multiple ER visits and was not told of her diagnosis until 5 ½ to 6 months later:

There was one specific incident in my healthcare that sticks out quite prominently. It was prior to having my gall bladder removed. I visited the emergency room department with severe pain. I had an ultrasound done and I was sent home with an OxyContin drug for pain management. I wasn't given a diagnosis, I was told to see my family doctor. Three months later, I had extreme pain—this is like 4 o'clock in the morning. I went to the emergency department and told them of my past ER visit and history (told them I had an ultrasound done and at that point I was taking pain management and sent home with a drug). Two months later, I went to my doctor with a problem and when he opened my chart he said, 'You got a problem with your gall bladder?' I said, 'I don't know, do I?' And, he passed me the doctor report: multiple Cholelithiasis.

This story supports that clients need to be included in care. Sharing information with the client potentially may have provided appropriate services in a timely manner.

**Language Barrier.** The use of clear language and understandable terms is deemed important for communication. Participant #8 offered a commentary on when a language barrier may interfere with communication:

I've heard other people say that sometimes there is a problem here in Newfoundland especially [because] they bring in foreign doctors, of course, from different Asian countries...and the patient themselves have problems understanding that particular doctor. If that family doctor is from India or somewhere, English is not one hundred percent and an older person who may [already] have typical problems to communicate with the doctor. You know, I can foresee a problem there.

When there is a language barrier with clients and healthcare professionals, information sharing and subsequently knowledge becomes a challenge.

Through sharing of further participant stories about themselves or family members, it became apparent that they value the opportunity to be involved in their healthcare decisions. The negative views of paternalistic healthcare, the lack information sharing, and possible language barriers impede the older adult's involvement in healthcare decisions. The absence of communication and clear explanations and the feeling of disrespect can potentially lead to an erosion of partnership.

For a true partnership to develop, both the older adult and healthcare professional have an active role to play. Partnership in healthcare implies that each person brings something to the relationship and contributes with all aspects of care decisions. Participant #8 states, "I think it is about you and how you relate to your doctor and you...." There must exist a reciprocal relationship where both the older adult and healthcare worker respect each other's perspectives, encourage the opportunity for discussion, and anticipate contributions from both parties to support collaboration. Participant #4 conveys the importance of being actively involved and independently seeking information about their health:

...like over the years there has been a tremendous change in attitude toward the importance of involvement with the patient or client and their healthcare decision-making and there's far more information out there more than there ever used to be and so it's available to anyone who wants to know more and, and I said, knowledge is power and I think that we're definitely in that era in this point in our life, in this point in time.

### **Chapter Summary and Conclusion**

The main purpose of this study was to explore the older adult perspective on participation in healthcare. Findings revealed that the participants preferred to be involved in their healthcare decisions. Utilizing the six concepts of healthcare involvement, supporting participation, older adult participation, factors influencing healthcare involvement, factors that encourage healthcare involvement, and characteristics promoting active participation, the overarching theme of this study was the healthcare experience should be a *true partnership* where older adults expect to work with healthcare professionals as equal partners in care with a shared goal to support their health. Three subthemes that emerged were communication, respect, and trust. All three must work together in unity to support true partnership. As a result of this study, true partnership can be described as being open to and inviting mutual communication in an atmosphere that encourages equal sharing of information, contributing to respect and the development of trust that results in a confident collaboration in care.

The positive responses of the participants relating to their current involvement in their healthcare decisions with their family doctor demonstrates the value of the physician-client relationship and how it contributes to overall satisfaction with their healthcare experience. Understanding the importance of this healthcare relationship and the subsequent level of perceived participation, can help nurses to identify components of relational care of importance

of older adults in encouraging client involvement. These findings can be incorporated by nurses into their own professional practice to improve truly collaborative participation in care.

When providing quality care to older adults, it is important to listen to their perspectives, understand their preferences, and listen to their stories to gain an enhanced understanding of their expectations regarding healthcare involvement. Patient participation is a broad and highly complex concept that can be part of a variety of situations (Florin, Ehrenberg, & Ehnfors, 2008). Connecting with older adults who participated in this study acknowledged that sharing their stories could assist nurses and other health care professionals gain an augmented understanding of what participative health care is for them. In the next chapter, these findings are discussed in more depth in the context of (a) a model developed based on the subthemes of communication, respect, and trust; and (b) the intent of action research.

## Chapter Five: Discussion

Participative healthcare involves all members of the healthcare team, including physicians, nurses, and clients. In the care model of client-centered nursing, the relationship between nurses and the older person is key to successful healthcare experiences (McCormack, 2003). To further substantiate client involvement, nurses have an ethical responsibility to ensure clients have a voice in their healthcare decisions. The Canadian Nurses Association (CNA) states that nurses must recognize, respect, and promote a person's right to be informed and make decisions (2008). As client involvement is essential, it is necessary that healthcare workers have an improved understanding of participation in healthcare and what it means to the older client. Healthcare will continue to be impacted by Canada's aging population, with older adults being the highest users of the healthcare system (Christensen, Doblhammer, Rau, & Vauperl, 2009). As this growing population continues to access healthcare services, it becomes increasingly necessary, as healthcare providers, to explore healthcare participation from an older adult perspective. Older adults were invited to participate in this study to share their healthcare experiences, thoughts, and advice using semi-structured interviews to provide an enhanced understanding of participative healthcare experience.

Action research is a form of collaborative inquiry requiring both the researcher and participant to generate greater knowledge on a particular issue in healthcare. The emphasis in all action research studies is the reciprocity between researchers and participants that seeks to empower those who have not traditionally had a voice (Speziale & Carpenter, 2007). Because of this, action research seemed an appropriate form of inquiry to provide the older adult the opportunity to share their perspective on participative healthcare, as this requires both parties being active participants, as mirrored by the concept of participation.

The continued involvement of the participants' during this action research study was crucial. 13 participants expressed interest in this study and demonstrated their desired level of involvement by sharing only what they felt comfortable to do so. By sharing their experiences, the participants guided the development of the aims of the study included in chapter one.

The semi-structured interviews provided only an initial discussion opening but the participants themselves guided the conversations by sharing their unique knowledge, experience and perspectives. Throughout discussions, the clinician-investigator ensured comprehension through clarification, paraphrasing and summarizing their expressed ideas to safeguard the participant voices were correctly noted. Participants were continuously provided an opportunity to add comments, restate their ideas for clarification, review statements and the opportunity to provide further insight to strengthen ideas and key concepts to ensure accuracy and appropriateness.

Once responses were reviewed, key themes were identified and provided back to the participants to review at the end of each interview. They were encouraged to share their thoughts and express if they thought ideas, key concepts needed revisions, modifications or recapturing their individual story meaning.

Once this was done, a further exploration was completed to identify key words and subsequently sub-themes which assisted in the development of the overall theme which was provided back to the participants to review for verification in the form of an executive summary draft. Each participant was provided the opportunity for discussion before a final draft was completed. Participants reported they felt involved in the process and appreciated the opportunity to ensure their true voice was heard. There were no reports from participants indicating that they did not feel involved in the process from the initial clinician-investigator contact to completion

of thesis. Their continued involvement ensured they actively contributed and guided the process understanding that their interest and willingness to share their unique stories were used to generate new knowledge regarding participative healthcare to enhance future nursing practice.

A major consideration of action research is to ensure that the story of the participant's remains the focus of the study. In writing up a project, the clinician-investigator must be able to demonstrate that they have developed new meaning from participant experiences (Williamson, Bellman & Webster, 2012). With this in mind, the following discussion will provide a deeper exploration of study findings supported by statements from the participants and current literature. This will ensure that this study is both accurate and accountable to participants who provided a new perspective to nursing knowledge.

### **A Model of True Partnership**

This study demonstrated that older adults prefer to be involved in their healthcare decisions, with a strong desire to be an equal partner in their healthcare experience. Reciprocity is evident in this study as the participants reveal that they don't expect to be fully in charge, nor do they expect to be totally reliant on the health care professional, rather they would prefer to have an experience where the healthcare professional and individual work together to come to the best solution possible, forging a true partnership. Through semi-structured interviews, reflective field notes, and stories received from the participants, a definition of partnership emerged. A true partnership can be described as open to and inviting mutual communication in an atmosphere that encourages equal sharing of information contributing to respect and the development of trust that results in a confident collaboration in care.

This study's findings can be visually represented in the following visual model, based on a Venn diagram representation of linked subthemes, to illustrate the conceptual theme of *true partnership*.

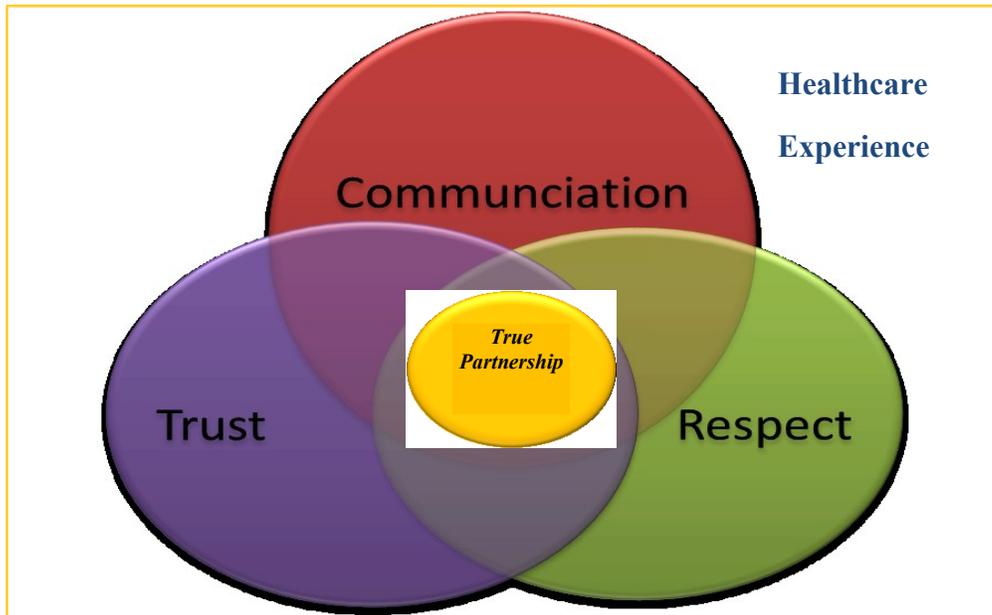


Figure 1 Model of relational subthemes important to a true partnership.

### **True Partnership**

This action research study found that older adults prefer to be involved in the healthcare decision making process. The participants in this study revealed they did not appreciate a paternalistic approach to care and felt they should always be involved in their own care. This study yielded similar findings, noted in the systematic review authored by Chewning, Bylund, Shah, Arora, Gueguen, and Makoul (2012), stating the number of patients who prefer participation has increased over the past three decades so that the majority of patients prefer to participate in decisions during the encounter.

From the older adult perspective, to forge a true partnership, the older adult must feel an equal and valuable member of the healthcare team coupled with the expressed willingness of the

healthcare provider to accept their perspective demonstrating mutuality. These findings are similar to the study by Eldh, Ekman, and Ehnfors (2010), which reported, that patients' descriptions of patient participation focused on having knowledge, rather than being informed, and on interacting with health professionals, rather than merely partaking in decision making (p. 26).

### **Communication**

The participants in this study emphasize that mutual communication is essential for a collaborative partnership that has a positive effect on the healthcare experience. Pivot Table 3 (p. 121) demonstrated a positive association between communication and participation suggesting that communication can positively influence the older adults' involvement in healthcare decisions. "The mutual exchange of information is an important contributor to satisfaction with health care decisions" (Pipe et al., 2005, p. 9). Open discussions between partners allow for both the older adult and the healthcare professional to have all the information needed to reach a shared goal in care. In a true partnership, communication involves the mutual sharing of information, using clear identifiable terms in understandable language, as well as the relevant access to information and the allowance of time to promote a meaningful discussion.

Communication is not one-sided. Communicating with seniors is not simply a matter of conveying your own message but involves an exchange of information, allowing clients or consumers to express thoughts and feelings as well as to convey objective information about their situation (Turcotte & Schellenberg, 2006). An open exchange of information and the mutual ability to ask questions supports participation. An absence of an invitation to exchange information may negatively affect care. If the older adult does not perceive the opportunity to express their perspectives, they may not share all relevant and required information. As Pipe et

al.'s (2005) study reports, "older adults may be at risk for exchanging limited information about health related issues, and they may also be less likely to give providers information that may be pertinent to making good health care decisions" (p. 10), which can negatively affecting care.

Participants acknowledge that communication is 'a two way street.' Both the health care professional and older adult client must both be active contributors. As Gantert et al. (2008) state, "seniors appreciated when a provider and client mutually took the opportunity to discover one another's strengths and limitations and to explore how, together, they might best achieve the client's goals" (p. 30). Older adults welcomed the opportunity to discuss their unique situations and seek valued information from their healthcare provider who considers their individual perspective.

Communication involves the exchange of information using words. To enhance communication and subsequently understanding, the healthcare provider must strive to provide a clear picture of the older adults' health situation using terms they can understand. The older adults in this study state that certain terminology used by healthcare professionals need to be presented in an understandable language to promote clarity. Using complex terms adds confusion. "You don't communicate with big words," states Participant #5. Refraining from using complicated medical terminology and explaining the health situation in simple straight forward words increases the older adults' understanding leading to a more meaningful and understandable encounter.

In a true partnership, the mutual exchange of information is important. It is equally important for the older adult to express thoughts and emotions, preferences and wishes, as it is for the healthcare professional to be open and honest in the sharing of accurate, up to date information, given their current knowledge and experience. Gantert et al., (2008) found similar

findings: “When senior clients did express their points of view, they believed that providers should accept those points of view and that they themselves should accept providers’ contributions to the relationship in return” (p. 30).

In a true partnership, access to health information appears to be a strong indicator for active involvement. When the older adult has access to pertinent health information (internet, health advice from a professional or general knowledge) it has a positive impact on their contribution to conversation. Access to relevant information is seen as an important prerequisite for patient participation (Florin, Ehrenberg, & Ehnfors, 2008). Participant #6 states, “...I would feel more confident leaving the office, if they would go over some of that [lab tests]....” Through open sharing of information, both the healthcare professional and the older adult client will have all of the appropriate information needed to make the best healthcare decision possible. When the older adult feels armed with appropriate information, it provides an opportunity for meaningful discussion about their healthcare needs. “This may relate to the amount of knowledge they have or the amount of knowledge that they perceive is necessary to make the decision” (Say, Murtagh, & Thomson, 2005, p.112). This study has similar findings to the study by Eldh, Ekman, and Ehnfors, (2010), which confirms patient participation means being considered a resourceful individual who comprehends, i.e., has and receives information corresponding to sharing knowledge and sharing perspective.

Older adults in this study state that in order for the sharing of perspectives to occur, allowance of time is an important factor to facilitate open discussions. Time allows the older adult to come prepared to ask questions and provides the healthcare professional time to respond and clarify questions that may arise in a non-hurried environment. Participant #5 states, “I have thought through before I went in, exactly what I want [to ask] because I don’t want to waste his

time and I don't want to waste my time." Preparedness allows all areas of care to be explored and clarified contributing to a more meaningful healthcare experience.

In a true partnership, communication is essential. Factors needed to promote communication are mutual sharing of ideas, using understandable language, access to relevant health information and time to promote an environment that encourages active involvement of the older adult in a meaningful healthcare experience.

Communication is essential in collaborative care. Nurses must encourage open discussions with their older adult clients to allow for the equal exchange of knowledge and expertise. Open communication involves mutual sharing of information using understandable terms to assure understanding contributing to participation. Open discussions allows for the equal exchange of knowledge, ideas, expertise, and perspectives. This information sharing invites all parties to participate in the decision making process in the best interest of the older individual.

### **Respect**

For collaboration to occur, there has to be an environment where the older adult feels equal to the healthcare professional. Patient participation requires that the patient experiences respect in his or her encounter with the health professional..." (Eldh, Ehnfors, & Ekman, 2006). Several participants' comments suggest mutuality is an important component in order to be an active participant in their health. Statements such as "You must not feel that doctors or other healthcare professionals are unapproachable" (Participant #1), "not have a God complex" (Participant #10), and "they don't have to be a snob" (Participant #12) reflect the desire to be valued as a person who can contribute.

The participants in this study also suggest that in order to have a true partnership, respect must be present. Respect involves knowing that other people have a perspective, an opinion, and ways of coping and solving problems that may differ (Gottlieb & Feeley, 2008). They stated that the older adult must value the knowledge and expertise of the healthcare professional, while it is equally important for the health care professional to value each person and appreciate their perspective. Participant #7 stated, “I really think they [healthcare professionals] should be sympathetic, considerate, and friendly because I know there are some healthcare professionals who think they are above everybody else and if they are young, they think they know it all. The older person won’t be able to talk to them.” The appearance of respect invites the older adult to feel valued for their unique perspective and subsequently invites the opportunity for discussion.

Older adults report that for respect to occur, they must feel on equal ground and have a mutual respect for each other perspectives, thoughts, and ideas. Participant #3 emphasized the value of respect, stating, “...the doctor herself spoke to me like I was...well I’m a real person and I’m not just a case...that this is my life and this is important to me....”

Within the healthcare encounter, respect promotes participation. Nurses must provide care where respect is evident. Respect is demonstrated when a culture of mutuality is apparent. When nurses show genuine interest in their older client and value their opinions, a respectful environment is recognizable. In a relationship where both personal and professional perspectives are valued, older adults and nurses can work together to make the best healthcare decisions possible.

### **Trust**

For a true partnership to develop, trust must be present. Pivot table # 2 (p. 120) demonstrated a strong relationship between length of time with family physician and the ability

to communication suggesting that a trusting relationship with the healthcare professional that is built over time coupled with the opportunity to communicate can contribute to increased involvement of the older adult in their healthcare decisions.

The building of trust encourages the older adult to participate in care decisions. Participant #10 states, “I have trust in [my physician] even though she is young. So, if I was dealing with [experiences] I didn’t feel was helpful, I would definitely be taking my business elsewhere.” The older adult must have trust in the healthcare professional that builds over time. Participant #5 states, “The doctor has always been there for me...if I needed anything.” Time allows each individual to build rapport, gaining an appreciation and understanding of each perspective. This is comparable to the Gantert et al. (2008) study, which found that the older population valued the opportunity to become acquainted with providers and likewise, the older adult would appreciate the opportunity for the healthcare provider to know them. When trust develops, the quality of the information that the person is willing to share often moves from superficial to personal (Gottlieb & Feeley, 2006).

Building trust leads to a level of comfort so that when and if the older adult experiences an emergent situation, they can be reassured that the healthcare professional’s judgment will be in the best interest of the client. As trust builds, it has a positive impact on the older adult’s health. Trust in healthcare providers is needed to encourage involvement. Trust facilitates individuals taking initiative to seek support from their healthcare provider that in turn, encourages participation. Participant #5 comments, “...you tell the doctor, I feel I need help in this.”

Trust is a vital characteristic of participation that builds over time. Trust is evident with continual older client support in every contact with the healthcare professional. When the client

appreciates that nurses support their best interest, nursing encounters will result in a more meaningful plan of care for the older adult.

### **Situating Findings in the Context of Action Research**

#### **Action**

Winter and Munn-Giddings (2001) state that action research is an ideal methodology for changing workplace practice due in part to the emphasis on reflection which generates new perceptions and understanding. My area of interest was on participation in healthcare, which stemmed from a personal encounter and that had a huge impact on me as a professional. It challenged how I practiced and what could be done to improve participation with the clients. The overarching aim of action research has been to improve professional practice and raise the standards for service provision (Morton-Cooper, 2000). This study highlighted aspects of participation expected from the older person that contributes to enhanced quality of care.

Action research is a form of qualitative inquiry where we intend to learn more about an issue to further enhance our practice asking questions about the conditions that are allowing the situation to be as it is and finding ways of changing the condition (McNiff, 2002). It is difficult to change my practice without gaining a heightened understanding of what it means to the individuals experiencing healthcare involvement. Exploring the concept of participation from an older adult perspective can provide insight into aspects of care needed to encourage involvement.

I adopted the action research methodology to explore the phenomena of participative healthcare from an older adult perspective because it encourages a collaborative approach to exploring a concept with the individuals who experience it. The older adult perspective can provide new knowledge on participation and how they experience it to provide a broader

understanding to nursing practice, offering changes that can be made to encourage and support older adult voice in care contributing to enhance nursing care.

### **Reflection**

I have over 20 years of nursing experience, much of which has been in the community health field. My education in nursing has allowed me to expand my nursing knowledge and strengthen care provision. Undertaking this Master's program, and subsequently this action research study, has challenged past practice. In my daily practice, I value each person as unique and believe that each individual should be respected for their distinctive perspective. As a core value in care, I believed this contributed to client-centered care.

Reflective practice is considered as a way to meaningfully assimilate theory and research into personal knowledge (Gustafsson, Asp, & Fagerberg, 2007). Looking back at past healthcare encounters, I believed the nursing care I was providing focused on information sharing. I prided myself on sharing information with my clients; I knew that current, relevant, and evidenced-based directives are important components for good care. However, upon reflection, I have come to realize that specific practices, such as influenza education during the fall flu season, while important, can be considered one-sided and deemed necessary without involvement or eliciting participation in decision-making. I thought I was providing quality care to my clients in that *I* shared all the relevant information to them in an attempt to have them follow what I felt was the best health advice. I asked my client's clarifying questions to ensure they had a clear understanding of what *I* was telling *them*. While I was very open with them and sharing my knowledge with them, it is now clearly apparent this was very unilateral communication.

Reflective practice is an internal and external agent that empowers the RN to learn through her own experience and facilitates understanding and meaning (Gustafsson, Asp, & Fagerberg, 2007). As a result of this study on participative healthcare, I realize that collaboration is an essential component to a participative healthcare experience, a concept where both sides share their perspective. I now have an enlightened understanding of what was missing in my client interactions: reciprocity. I had no idea what my client was thinking! I am now able to understand that all my encounters must support a true partnership. This includes an active role of both me and the older adult to have a responsibility to mutually share perspectives in a respectful manner, enhancing trust.

### **Transformation**

Reflective practice is a commitment to life-long learning that characterizes the professional growth and development of nursing within the profession (Gustafsson, Asp, & Fagerberg, 2007). Reflecting on my past practice has allowed me to acknowledge what was missing from my nursing practice: a true partnership. Through the sharing of the perspectives, the participants in this action research study emphasized the importance of a true partnership built on open sharing communication in a respectful environment built on trust.

**Communication.** Information sharing should be encouraged with clients involving the mutual exchange of perspectives. Not only will I share my knowledge and expertise, I will also invite my older clients to share their thoughts and insights. I will allow time for open discussion, focusing on areas the older adult feels is important to them, supporting a mutual sharing of perspectives.

**Respect.** I will endeavor to get to know my clients. I will not only focus on their health concern but also inquire about their personal situation, showing a genuine interest in all aspects

of their lives. Gaining an enhanced understanding of their thoughts and beliefs and valuing their unique circumstances will allow me to provide meaningful encounters that support respect for the individual.

**Trust.** I will strive to hear and listen to my older adults' opinions and information that they chose to share with me. I will be there in the moment, attempting to understand them as an individual. When the older adult feels valued, trust begins. When older adults trust their healthcare provider, they will be more willing to share information, resulting in a positive healthcare experience.

This action research study included participants sharing personal stories about their healthcare encounters to provide an understanding of their expectations on involvement. During this action research study, participants also underwent a transformation. The process of providing a voice to the older adults and exploring their personal experiences further solidified the strong desire of these participants to be involved in their healthcare decisions. I believe that having their stories heard in a supportive atmosphere gave them reassurance and motivation to continue to be involved in health matters. Several participants reported that after talking about encounters, they understood the importance of their involvement and would take measures to remain actively involved. One participant, upon reviewing findings, remarked, "Trust, communication and respect is what I expect when I'm involved in the healthcare system."

### **Professional Development**

Action research often begins with the question, "How do I improve my work?" My personal interest began from a personal healthcare encounter that was less than admirable, essentially an experience that was the antithesis of my study, taking away a person's inherent value due to a nurse's actions. This experience challenged me to ask myself, "Do I make my

clients feel this way in my nursing practice?” This question ultimately encouraged me to explore participation in the healthcare experience. Inquiring how one improves work implies the social intent that one person improves their work for their own benefit and the benefit of others (McNiff, 2002).

This study emphasized three vital components needed for a participative healthcare experience: open communication, respect, and trust. When all three are present, a true partnership can thrive, leading to quality nursing care. Armed with this new knowledge for participative care and a new commitment for collaborative partnership has positively impacted my personal nursing practice. As a current nursing practice instructor, I continually ensure that my students are aware of the importance of partnership as an important component of care. They are becoming experts in the field of nursing, but the older adults are experts in themselves. Only when mutual sharing of information occurs in a respectful environment that encourages trust can a true partnership evolve that is open to and inviting mutual communication in an atmosphere that encourages equal sharing of information, contributing to respect and the development of trust that results in a confident collaboration in care.

### **Chapter Summary and Conclusion**

In summary, older adults prefer to be involved in their healthcare decisions and be an equal member of the healthcare team. The healthcare professional and the older adult work together to openly discuss their unique perspective in a respectful environment. This reciprocity develops trust over time. True partnership is built upon mutual communication, respect, and trust, contributing to a meaningful healthcare experience.

The analysis revealed that older adults prefer to be an active participant in their care. A major theme that emerged in this study was a true partnership, where older adults expect that

they work with healthcare professionals as an equal partner in care to support their health. Three sub-themes that emerged were communication, respect, and trust. All three equally needed to work in collaboration with health care decisions. As a result of this study, true partnership can be described as open to and inviting mutual communication in an atmosphere that encourages equal sharing of information, contributing to respect and the development of trust that results in a confident collaboration in care.

## Chapter Six: Conclusions and Recommendations

Healthcare will continue to be impacted by Canada's aging population, with older adults being the highest users of the healthcare system (Christensen, Doblhammer, Rau, & Vauparl, 2009). This trend will change the healthcare system and how we offer services to the older population. With healthcare moving from a traditionally prescriptive model to being more person-centered and individually focused, it is essential that nurses have an understanding of how to work collaboratively with the older population group.

Healthcare professionals recognize the importance of an individual's involvement in their care. Patient participation in clinical decision-making leads to improved patient satisfaction with care (Johansson et al., 2002) and is identified as an important indicator of quality nursing care (Kunaviktikul et al., 2005) contributing to a more meaningful healthcare encounter. Therefore, it is important that we gain an understanding of how participation is perceived by the older population. Nurses, as one of the key providers of care for older people, are well positioned to advance the involvement of older people in all aspects of their care (Cook & Klein, 2005). It is essential that nurses gain an understanding of how older individuals perceive their participation in their care so we can encourage and support their involvement in healthcare decisions.

The title of this action research study is: *Invoking Silvern Voices in Healthcare: Transforming Practice by Engaging Older Adults in Collaborative Partnerships*. The phrase 'silvern voices' was taken from the song *Ode to Newfoundland* which represents the beautiful sounds that can be heard on the island (such as waves on rocks, wind through trees) making Newfoundland unique. This phrase was chosen to be included in the title because this study represents the voices of the older adults, listening to their healthcare experiences to contribute to enhanced nursing care.

## Summary

This action research study explored participative healthcare from an older adult's perspective. Thirteen older adults, ranging from sixty-six to seventy-seven years of age, participated in this study to share their healthcare experiences, thoughts and advice using semi-structured interviews to provide an enhanced understanding of the participative healthcare experience. During initial analysis, six main concepts emerged: healthcare involvement, supporting participation, older adult participation, factors influencing healthcare involvement, factors that encourage healthcare involvement, and characteristics promoting active participation. Exploration of these concepts guided the understanding of the older person's preference with healthcare involvement and the development of the overarching theme of true partnership.

The analysis revealed that older adults prefer to be active participants in their care. The major theme that emerged in this study was a true partnership, where older adults expect that they work with healthcare professionals as an equal partner in care to support their health. Three sub-themes that emerged were communication, respect, and trust. Refer to Figure 1: Model of relational subthemes important to a true partnership (p. 67). All three together were needed to work collaboratively with healthcare decisions. Communication is mutual, where both the older adult and health care professional share their unique knowledge, expertise, and perspective in an open environment that encourages the open sharing of ideas. Demonstrating respect for each unique perspective and establishing trust in one another's abilities contributes to confident collaborators in care. "Involvement in decision-making is the main issue for participation; patients describe participation mainly as sharing knowledge and sharing respect" (Eldh, Ekman & Ehnfors, 2010).

Armed with an enhanced understanding of how older adults perceive involvement in their own healthcare decisions allows nurses to make changes to our daily practice to support active participation. Incorporating strategies that foster communication, respect, and trust contributes to a healthcare experience that develops a true partnership.

### **Recommendations**

This study provided a voice for older adults' to share their perspectives on participation by exploring their relationship with their family doctor. In the context of this healthcare relationship, it was noted that the success of this relationship in the community setting had a positive impact on perceived involvement with their healthcare decisions making the healthcare experience more meaningful for the older adult.

Client involvement in healthcare is necessary to successfully meet the client's satisfaction with healthcare encounters therefore is an important consideration in nursing practice, especially with older adults. This action research study explored participation in healthcare from the perspective of thirteen older adults which provided insight into what inspires involvement. Study findings revealed that older adults prefer to be involved in their healthcare decisions. The major theme that emerged in the analysis was true partnership, where older adults expect that they work with healthcare professionals as equal partners in care. To build a true partnership with the older adult population, the components of mutual communication, respect, and trust are needed to work in unity.

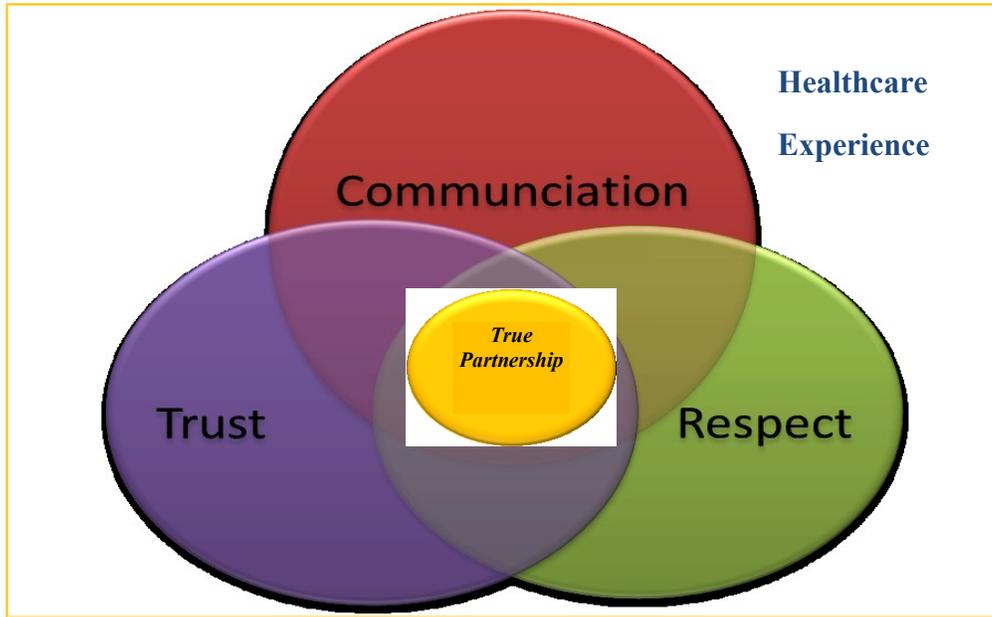


Figure 1 Model of relational subthemes important to a true partnership.

This model represents a strong visual representation of true partnership that can be utilized in any area of nursing where nurses work with clients to enhance the healthcare experience.

**Communication.** Communication is essential in collaborative care. Nurses must encourage open discussions with their older adult clients to allow for the equal exchange of knowledge and expertise. Open communication involves mutual sharing of information using understandable terms to assure participation. Open discussions, allow for a reciprocal exchange of knowledge, ideas, expertise, and perspectives. This sharing of information invites all parties to participate in the decision-making process that is in the best interest of the older individual.

**Respect.** Within the healthcare encounter, respect promotes participation. Nurses must provide care where respect is evident. Respect is demonstrated when a culture of mutuality is apparent. When nurses show genuine interest in their client and value for their opinions, a respectful environment is recognizable. In a relationship where both personal and professional

perspectives are valued, older adults and nurses can work in tandem to make the best healthcare decision possible.

**Trust.** Trust is a vital characteristic of participation which builds over time. Further, trust is evident with continual client support in every contact with the healthcare professional. When the client appreciates that nurses supports their best interest, nursing encounters will result in a more meaningful plan of care for the older adult.

Providing the opportunity for older adults to have a voice and be heard allows healthcare professionals, such as nurses, to take advice from the individuals with whom they work in order to enhance the care they provide. Including older adults in decisions about their own healthcare contributes to improved health outcomes for both the older adult and healthcare professional, which influences a positive healthcare experience. True partnerships exist when both the healthcare professional and the client bring their unique knowledge and skill to work together. Creating and maintaining a supportive environment where both individuals feel comfortable to share their perspectives through open discussions in a respectful manner over time develops trust to provide a voice for older adults in care.

The model of true partnership with the essential components of communication, respect and trust can also be considered in various areas within the practice of nursing.

**Nurse as researcher.** This action research study explored participative healthcare from an older adult perspective and highlighted the preference for involvement. As the importance of client involvement in care continues to gain momentum, further studies on participation from the older adult perspective are warranted to further enhance the depth and breadth of the meaning of involvement. The greater healthcare's understanding of participation from the older client perspective can better align healthcare professional's resources to support the older adult's

expectation with care. Studies may include individuals from various cultures and socio-economic backgrounds to investigate if the preference for active involvement is also true for the diverse population of the elderly.

**Nurse as educator.** This study emphasized that older adults prefer to be involved in care. Carrying on with this trend, it then becomes evident that nurse educators should include older clients in educational endeavors. Including the elderly perspective in educational environments on inclusiveness can support textbook participative theory. Developing community panels where students can ask older clients themselves what the expectation is concerning involvement in care can allow the individual student to gain experiential knowledge in the classroom setting.

**Nurse as clinician.** This study brought forth the importance of the older client and their preference for involvement in care. As a practicing nurse, it is important to be dedicated to developing a true partnership with the older client. Being attentive to their expectation of care involvement, showing a genuine interest in mutual exchange of perspectives and a focus on encouraging and supporting their care needs can eliminate the many challenges with care provision that impedes nursing care such as time restraints and task completion. With a focus on developing a true partnership, time restraint will not be a barrier to care. This reframing of care provision can contribute to active participation that is expected by the older adult population ultimately resulting in quality care and positive health outcomes. Promoting client involvement in care is paramount for client-centered care, especially with the older population, as this study revealed that older adults prefer to be active participants.

When the nursing profession has a clearer understanding of expectations of the older adult population to be active participants, encouraging and supporting their voice in care

decisions ensures their needs are being met in a meaningful way, contributing to improved health outcomes and enhanced quality care.

Healthcare is dynamic, always evolving to provide the best possible quality care. It is important to continue research to ensure we meet the needs of clients who access services. From this action research study, several areas emerged that warrant further investigation. Continuity of care and perceived health status appeared to be strong indicators for participation. Also, it was apparent that a consistent healthcare provider was an indicator of quality care. Methods to explore this area, such as surveys and focus groups, may support this study's findings and further define the concept of participation and ultimately have a positive impact on nursing practice strategies in care provision.

### **Conclusion**

“Population aging in Canada is expected to accelerate between 2011 and 2031, as all people in the large cohort of baby boomers reach their senior years” (Milan, 2011). With this growing trend, it is important for nurses to gain an enhanced understanding of health issues concerning the older adult population. Participative healthcare is an important component of care for all people, including older individuals. It contributes to improved health outcomes and it is vital that healthcare professionals (especially nurses) have an understanding of participative healthcare from an older adult perspective, as nurses often work along-side them in their healthcare. The knowledge and experiences that older individuals will share in this action research study will provide insight into participative healthcare and make a valuable contribution to current nursing literature.

Action research has been quite recently adopted by healthcare professionals seeking to develop aspects of their practice (Williamson, Bellman, & Webster, 2012). As older adults

continue to be a growing population that will utilize healthcare services, it was important to explore concepts relating to care provision. The rise of consumerism, a lack of tolerance for paternalism, and the development of client-centered approaches have led to a growing acknowledgement that clients are legitimate and indispensable members of the healthcare team (Gantert et al., 2008). This action research study provides an enhanced understanding of participative healthcare from an older adult perspective. As healthcare professionals, it is necessary to hear the voices of the people we serve in an effort to enhance quality care. This study demonstrates that older adults prefer to be involved in their healthcare decisions. A major theme that emerged in this study was true partnership, which can be described as open to and inviting mutual communication in an atmosphere that encourages equal sharing of information, contributing to respect and the development of trust that results in a confident collaboration in care.

Today's healthcare environment is focused on client inclusiveness. From the historical physician-guided care to the evolution of Primary Health Care where clients are encouraged and supported to be involved in their healthcare decisions, it remains essential that the practice of nursing remains client focused.

The Canadian Nurses Association (CNA) advocates for nurses to provide care that understands individuals have a right and responsibility to be active partners in their care (CNA, 2005). The development of the true partnership model demonstrates the foundational aspect of Primary Health Care (PHC) ensuring individuals, especially older adults, are actively involved in their care provision in the community setting.

The importance of community client partnerships is further supported by the Canadian Community Health Nursing Practice Model that states nurses must build professional

relationship and partnerships. Community Health Nurses must ensure individuals are active partners in defining health issues and in making decisions that affect their health and well-being (CHNC, 2013). The formation of partnerships with individuals ensures nurses continue to provide care in a way that supports client involvement which supports the foundational aspect of PHC that today's healthcare environment is built on.

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### Appendix A: Poster

As vital members of society, older adults possess valuable knowledge and experiences that can impact nursing practice.



#### **Nurses need to hear from you!**

A nurse's role is to encourage and support the older individual's involvement in their healthcare decisions. *Your* healthcare experiences will help nurses better understand *your* perspective into healthcare involvement.

Would you like to share your healthcare experiences? If so, I would like to connect with you. The stories you share will provide a voice into the future of nursing. If you are interested in talking with a nurse about your role in healthcare, or would like to hear more about this study, please contact Stacy Oke (nurse-clinician) via phone more information.

**Appendix B: TCPS 2: Core Certificate of Completion**

**PANEL ON  
RESEARCH ETHICS**

Navigating the Ethics of Human Research

**TCPS 2: CORE**

# *Certificate of Completion*

*This document certifies that*

**STACY OKE**

*has completed the Tri-Council Policy  
Statement:*

*Ethical Conduct for Research Involving Humans  
Course on Research Ethics (TCPS 2: CORE)*

Date of Issue: **28 May, 2012**

### **Appendix C: Letter to Potential Participants**

Dear Sir/Madame.

My name is Stacy Oke and I want to thank you for taking the time to consider sharing your stories and experiences of participating in the healthcare system.

I am a graduate student with Trinity Western University preparing to do a capstone project as a requirement for my Masters of Science in Nursing program. I want to explore healthcare from the older adults' perspective. With the aging population in Canada, I believe it is important for nurses to be prepared to work in collaboration with the older adult population in a community setting. As participative healthcare improves health outcomes, I wish to explore experiences and beliefs that have either encouraged or discouraged your involvement in your healthcare decisions.

Older adults are vital to our community possessing unique knowledge and experience that can have a positive impact with nursing. Sharing your perspective now about participative healthcare can highlight aspects of care that can be adapted in order to provide you with quality care in the future. The stories you share about your healthcare involvement will be communicated with other nurses and healthcare providers to enhance the care you receive in the future. Your involvement with this study will provide the foundation for enhanced knowledge about participative healthcare relating to older adult nursing practice.

If you are interested, please read the accompanying material for a more thorough explanation of this study. Please feel free to contact me anytime for more information by phone.

I am looking forward to hearing from you!

Kind Regards

Stacy Oke RN BN CCHN(c)

## **Appendix D: Informed Consent Form**

### **Principal Investigator:**

Stacy Oke RN BN CCHN(c)

Masters of Science in Nursing (Candidate)

Trinity Western University

### **Purpose:**

Today in the healthcare environment, individuals are expected to be an active member of the healthcare team; encouraging individuals to be more involved in their own healthcare decisions. Nursing practice has not always encouraged or supported an older persons' involvement. Nurses have not been good about listening to find out what older adults believe is participatory. With our aging Canadian population, nurses must prepare to provide care in partnership with older adults to enhance their healthcare experience. Giving older adults an opportunity to have a voice and by sharing older adult experiences on their healthcare involvement can help nurses improve care to older adults in a way they expect and understand.

The purpose of my study project is to gain an enhanced understanding of participative healthcare from an older adult perspective and to communicate this understanding with experiential stories to make a valuable contribution to existing nursing literature.

Older adults are a vibrant group with much knowledge and great life experiences. Sharing your healthcare perspectives can have a positive impact on nursing care of the future.

**Procedure:**

The information for this study will be conducted using a one-time interview process (face to face or by telephone) that will be approximately one hour in duration. You will be asked a series of questions that will seek your perspective on your involvement in healthcare. The interviews will be conducted in a private setting of your choosing and audiotaped so that further analysis can occur. No identifying information will be included when the interview is transcribed.

The information that will be collected will include your (and others) responses to the posed questions. The interviews will be pooled and be transcribed by a professional transcriptionist who will sign a confidentiality agreement. The information will be analyzed for content, themes and concepts. This analysis will be returned to you for confirmation that your perspective has been included. You have the opportunity to modify, remove or offer new information that might not have been captured during the interview. Once this data has been verified by you, the information obtained will be written up in a required document (Capstone Project Report) for the completion of a Master's of Science in Nursing program at Trinity Western University. This information will be communicated in a report that will be a valuable contribution to current nursing literature. You will be forwarded a written copy of the final report if requested.

**Potential Risks:**

There are no known associated risks to participation in this study.

**Potential Benefits:**

There are direct benefits to you in participating in this study. In engaging in a discussion on participative healthcare, you will gain an understanding the concept of participative

healthcare and potentially identify and/or strengthen your thoughts and actions deemed important to be an active member of your healthcare team. Indirectly, the perspective you provide will highlight the term participative healthcare for older adults which can positively impact yours and your generation's healthcare experience in the future. Finally, your knowledge and experience that you share will be a valuable contribution to the nursing profession and potentially influence nursing care to be more encouraging and supportive of participative healthcare.

**Confidentiality:**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or required by law. All documents will be identified by a coded number and kept in a locked filing cabinet or on a secure, password protected hard drive. Data will be compiled to analyze concepts, patterns and themes. Anything published will be short segments that support these themes that are without identifying information

An encrypted memory stick will contain the transcribed interviews. The consent form and the information obtained will be stored in separate secured filing cabinets as an extra safety measure.

If a participant should withdraw, their information that they provided (if any) will be disposed of in a secure and confidential fashion and not included in the study findings.

However, I fully acknowledge that the information obtained in the study will be used in nursing publications or presentations without identifying any participants.

**Consent:**

Your participation in this study is entirely voluntary. You may refuse to participate or withdraw from this study at any time without jeopardy to my future healthcare encounters. If you

wish to discontinue your participation in this study, you will continue to be treated in the usual and customary fashion. Upon study completion, data will be securely stored for 7 years. Then will be disposed of confidentially using secured measures.

**Compensation:**

This project is not being funded. However, as a thank you for participating, coffee and doughnuts will be provided during face to face interviews. For the telephone interviews, a \$5.00 Tim Horton's Gift card will be mailed to you. A thank you card will be provided to you upon completion of the study.

**Contact Information:**

If you have any questions or desire any information with respect to this study, you may contact Stacy Oke.

Contact for concerns about the rights of research participants:

If I have concerns about my treatment or rights as a research participant, I may contact the Office of Research, Trinity Western University.

If interested, a useful website that may be helpful to answer some of my questions about participating in a research study can be found at [www.pre-ethics.gc.ca](http://www.pre-ethics.gc.ca).

**Signatures:**

This study has been explained to you and you have had all of your questions about this study answered to your satisfaction. Your signature below indicates that you have read and understood this consent form. You consent to have your responses put in confidential form and kept for further use after study completion. The information obtained will be kept secure for 7 years. After that time, the information will be destroyed using a secure manner. You will receive a copy of this form for your own personal records.

Signature of Participant

Date

Printed Name of Participant

Signature of Researcher

Date

### Appendix E: Participant Questionnaire

- 1) How would you rate your own health?  
Excellent Good Okay Needs Improvement Poor
- 2) In the last year, how often have you visited your family doctor?  
Less than 5 times 5-10 11-15 more than 16
- 3) In the last year, how many times have you visited an Emergency Department or Urgent Care setting?  
Less than 5 times 5-10 11-15 more than 16
- 4) Do you have a family doctor? If so, how long have you had this doctor?  
Under 6 months 6 months to a year One to three years More than three years
- 5) How would you describe your relationship with your family doctor in regard to your ability to share your health concerns?
  - A) I can easily talk to him/her about my health concerns and feel he/she takes time to listen
  - B) I can often talk to him/her about my health concerns and feel he/she tries to listen
  - C) I can sometimes talk to him/her about my health concerns but feel rushed
  - D) I do not feel I can talk to him/her because he/she is not interested, too busy, or is simply difficult to talk to
- 6) How important is it that you are involved in your healthcare decisions? (Very important being always voice your wishes and not important at all being no desire to be involved).  
Very Important Important Neutral Not Important Not Important At All
- 7) How do you respond to this statement, "A doctor 'knows best' and a patient's role is to listen and follow his/her advice."  
Strongly agree Agree Neither Agree nor Disagree Disagree Strongly Disagree
- 8) Do you feel that there are always opportunities for your involvement in healthcare decisions? (See scale below). Why or why not?  
Always Sometimes Neutral Rarely Never
- 9) Would you like to be more involved in your healthcare decisions? If so, what would your involvement look like? If not, please share an example of what this might look like.
- 10) Thinking of your last healthcare experience, or a different one, how were you involved in the discussion on your health need?
- 11) Do you feel there might a time when your input into healthcare decisions is not needed? Please explain. (Prompt: ER vs. GP visits, unable to speak for yourself).

12) Family members can support older adults in their healthcare decision-making. Please share a story about how your family is involved with your healthcare?

13) Do you believe that your age has had a positive or negative impact on the level of care you received? Can you think of an experience where this was the case?

14) Can you tell me about a healthcare experience when you felt like you were encouraged to be involved in your own health care (Prompt: Did the healthcare professional ask for your input/wishes?) This can be either at your family doctor, as a patient in a hospital, specialists and/or from a previous family members' hospitalization which you were involved.

15) What factors were present that encouraged your involvement?

16) Can you tell me about a healthcare experience when you felt like you were not encouraged to be involved in your own health care?

17) What factors were present to hinder your involvement?

18) What are some characteristics you feel the older adult must possess to be involved in their healthcare?

19) What are some characteristics you feel the healthcare professional must possess to encourage your involvement in healthcare decisions?

20) We are now at the end of our discussion. Is there any other comment, question or experience you would like to share?

### **Demographics**

Just a quick couple of demographic questions before you go...

Male/Female

First Language:

Years of Education:

Job before retirement:

Year of Birth:

Country of Birth:

Cultural/Ethnic Family Background:

Which province do you reside in currently?

Thank you once again for taking the time to talk with me. Your contribution to the project is very valuable.

## **Appendix F: Literature Review**

**April 23, 2012**

**Database:** Medline (with full texts) (EBSCO*host*)

**Key Phrase:** Healthcare Participation - 3061 Articles Refined by full text (dates 2007-2012)

### **8 Relevant Articles:**

- 1) Factors influencing older patients' participation in care: a review of the literature
- 2) Shared decision-making. Medical groups embrace dawn of new day.
- 3) Working together to improve the care of older people: a new framework for collaboration
- 4) Health promotion attitudes and strategies in older adults
- 5) INTER-ETHICS: TOWARDS AN INTERACTIVE AND INTERDEPENDENT BIOETHICS
- 6) A comparison of the concept of patient participation and patients' descriptions as related to healthcare definitions
- 7) Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world
- 8) Arming patients to partner in their care

**Key Phrase:** Senior Healthcare Participation - 6 articles (dates 2007 – 2012)

### **1 Relevant Articles:**

- 1) Perspectives of healthy elders on advance care planning

**April 25, 2012**

**Database:** CINAHL( with full text)

**Key Phrase:** Healthcare Participation - 459 articles Refine by full text articles (dates 2007-2012)

**2 Relevant Articles:**

- 1) Power to the People
- 2) The Involvement of Service Users in Nursing Education

**Key Phrase:** Senior healthcare participation - 6 articles Refine by full text (dates 2002-2012)

**Relevant Articles:** None of relevance

**Key Phrase:** Older Person Participation – 90 articles Refine with full texts

**4 Relevant Articles:**

- 1) Ask the Experts: Person Centered Care
- 2) Patient participation on a ward for frail older people
- 3) Independent living, technology and ethics
- 4) Older persons' experience of being assessed for and receiving public home

help: do they have any influence over it?

**Monday, May 14, 2012**

**Database:** CINAHL with full text (2000 – 2012)

**Key Phrase:** Best Practice (Results: 2839)

**2 Relevant Articles:**

1. The role of a research nurse in translating evidence into practice.
2. So You Want to Change Practice: Recognizing Practice Issues and

Channeling Those Ideas

**Key Phrase:** Knowledge Translation (Results 742 Dates 2005 – 2012)

**1 Relevant Article:**

1. Applying knowledge to generate action: a community-based knowledge translation framework.

**Key phrase:** Action Research

**4 Relevant Articles**

1. Introducing evidence into nursing practice: using the IOWA model.
2. Participation in perspective: reflections from research projects.
3. Demystifying nursing research terminology: Part 2.
4. The nurse's role as specialist practitioner and social activist

**Tuesday, May 15, 2012**

**Database:** CINAHL with full text

**Key Phrase:** Nursing Models (Dates 2005 – 2012) Results 4191

**5 Relevant Articles:**

1. Exploring clinical wisdom in nursing education.
2. Participation in perspective: reflections from research projects.
3. An integrated ethical decision-making model for nurses.
4. Duties of the patient: A tentative model based on metasynthesis.
5. Exploring compassion: implications for contemporary nursing. Part 2.

**Thursday, May 17, 2012**

**Database:** CINAHL with full text

**Key Phrase:** Ageism (366 results, date range 2005 – 2012)

**7 Relevant Articles:**

1. The little things are hugely important in improving care for older people
2. Age concern
3. Socially constructing older people: examining discourses
4. Ageism is rife in health care
5. BELIEFS ABOUT AGING: IMPLICATIONS FOR FUTURE EDUCATIONAL PROGRAMMING
6. Storytelling reveals the active, positive lives of centenarians
7. Caring for the older person

**June 5, 2012**

**Database:** CINAHL with full text (2008-2012) 163 results

**Key Phrase:** Aging challenges

**3 Relevant Articles**

- 1) Aging in the 21st century: the nursing challenge
- 2) From the front line. Time to challenge the stereotypes of
- 3) A journey called aging: challenges and opportunities in

**September 2012**

**Database:** CINAHL with Full Text

**Key Phrase:** Patient Agency **1371 Results** (2005-2012)

**Relevant Articles:** 0

**Database:** CINAHL with Full Text (2005-2012)

**Key Phrase:** Older Adult Voice **29 Results**

**Relevant Articles:** 1

- The experience of being listened to: a qualitative study of older adults in long-term care settings

**Database:** CINAHL with full text (2005-2012)

**Key Phrase:** Older Adult Involvement **104 results**

**Relevant Articles:** 3

- Improving older people's involvement in health and in care decision-making
- Perceived involvement in decision-making as a predictor of decision satisfaction in older adults
- Involvement of older people in care, service and policy planning

**Database:** CINAHL with full text (2005 – 2012)

**Key Phrase:** nurse patient relationships **1439 articles**

**Relevant Articles:** 3

- Elderly patients' and residents' perceptions of 'the good nurse': a literature review
- How person-centered care can improve nurses' attitudes to hospitalized older
- Aging populations: the challenges ahead

**December 13, 2013**

**Data Base:** CINAL Full Text (Year 2007 – 2013)

**Key Phrase:** community environment and patient centered care (53 articles)

2 Relevant Articles

- 1) Obtaining consensus about patient-centered professionalism in community nursing: nominal group work activity with professionals and the public
  
- 2) Primary care and care for older persons: Position Paper of the European

**Key Phrase:** older adults and health care experience (119 Articles)

1 Relevant Article

- 1) Professional carers' perspectives on participation for older adults living in place.

**Key Phrase:** Nurse Patient Relationships (1,355 Articles)

2 Relevant Articles

- 1) Trust in nurse–patient relationships: A literature review
  
- 2) The case for concordance: value and application in nursing practice

**Key Phrase:** Older adult and self-determination (19 Articles)

1 Relevant Article

- 1) The case for concordance: value and application in nursing practice

**Key Phrase:** Older adult and Individualized care (28 Articles)

1 Relevant Article

- 1) The ACES Framework: Guiding Nursing Education and Clinical Practice

**Key Phrase:** Older adult and Autonomy (62 Articles)

- 1) Autonomous decision-making and moral capacities

**Key Phrase:** Older adult and shared decision-making (13 Articles)

**Key Phrase:** Older adult and Respect (94 Articles)

**Key Phrase:** Older adult and Participation (1, 227 Articles)

NO relevant Articles

**February 1, 2014**

**Database:** University of Calgary Library 2005 - 2014

**Key Phrase:** Client Involvement in Nursing (678 Articles)

**3 Relevant Articles:**

- 1) Client involvement in home care practice: a relational sociological perspective
- 2) Treatment Planning as Collaborative Care Map Construction: Reframing Clinical
- 3) The Key to Me: Seniors' Perceptions of Relationship-Building with In-Home Service Providers

**April 2014**

**Database:** CINAHL (full text)

These articles were not considered because they referred to older adults with dementia, Long Term Care, end of life care, acute care or focused on mental health concerns.

**Key Phrase:** partnership models of care

**Articles Retrieved:** 102 (Relevant Articles: 3)

**Dates:** 2007 – 2014

- 1) The trifocal model of care: Advancing the teaching – nursing home concept
- 2) The partnership care delivery model: an examination of the core concept and the need for a new model of care
- 3) Person-centeredness in gerontological nursing: an overview of the literature

**May 2014**

**Database:** CINAHL (with full text)

**Key Phrase:** Patient Engagement Dates 2005 - 2007

**Articles Retrieved:** 699 (6 Relevant Articles :)

**Articles:**

- 1) Nurses, Health Literacy & Patient Engagement
- 2) PATIENT ENGAGEMENT: Clinicians and Culture Play Important Roles
- 3) Patient Participation: An Emerging Nursing Issue
- 4) Improving patient engagement... George Bo-Linn

- 5) Nursing group wants patient engagement
- 6) Patient-Centered Care and Community Engagement

**Key Phrase:** Patient Satisfaction and Older Adult

**Articles Retrieved:** 186 (Relevant Articles 3)

**Articles**

- 1) Listening to Older Adults: Elderly Patients' Experience of Care in Residency and Practicing Outpatient Clinics
- 2) Morbidity and older persons' perceptions of the quality of their primary care
- 3) Perceived involvement in decision-making as a predictor of decision satisfaction in older adults

**Table 1***Characteristics of Participants*

Characteristic		Percentage
<b>Age</b>		
65-70	9	69
71-75	3	23
76-80	1	8
<b>Gender</b>		
Female	9	70
Male	4	30
<b>Education</b>		
High School	13	100
Secondary	10	77
<b>Language</b>		
English	13	100
Other	0	0
<b>Residing province</b>		
NL	9	69
AB	3	23
BC	1	8

**Table 2***Participant Self-perception About Their Health and Healthcare Involvement*

Perception	Total (N = 13)	%
<b>Self-rated health</b>		
Excellent	2	15
Good	9	70
Okay	0	0
Needs improvement	2	15
Poor	0	0
<b>Family doctor visits</b>		
Less than 5 times	9	70
5 – 10 times	3	23
11-15 times	1	8
More than 16	0	0
<b>Family doctor</b>		
Yes	13	100
No	0	0
<b>Importance of healthcare involvement</b>		
Very important	12	92
Important	1	8
Neutral	0	0
Not important	0	0
Not important at all	0	0
<b>Communication with family doctor</b>		
Easily talk about concerns	12	92
Often talk about concerns	0	0
Sometimes talk about concerns	1	8
Don't talk about concerns	0	0
<b>Length of relationship with family doctor</b>		
Under 6 months	1	8
6 months to 1 year	0	0
1 to 3 years	1	8
More than 3 years	11	85

**Table 3***Ability to Communicate with Physician and the Perceived Opportunities for Participation*

Ability to Communicate with Physician & Opportunities for Participation	Participant Responses (N)
I can easily talk and he/she takes time to listen	12
Always opportunities for participation	8
Sometimes opportunities for participation	4
Rarely/never opportunities for participation	0
I can often talk and he/she tries to listen	0
Always opportunities for participation	0
Sometimes opportunities for participation	0
Rarely/never opportunities for participation	0
I can sometimes talk but feel rushed	1
Always opportunities for participation	0
Sometimes opportunities for participation	1
Rarely/never opportunities for participation	0
I can't talk because he/she is not interested	0
Always opportunities for participation	0
Sometimes opportunities for participation	0
Rarely/never opportunities for participation	0