A Narrative Inquiry of Older Adults' Stories of Choosing to Not Share Information with Health Care Professionals

by

Shelagh Marie Brennan
RN, from Douglas College, 1981
BSN, from University of Victoria, 2003

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

MASTER OF SCIENCE IN NURSING

in the Faculty of Human and Social Development

Supervisory Committee

A Narrative Inquiry of Older Adults Stories' of Choosing to Not Share Information with Health Care Professionals

by

Shelagh Marie Brennan
RN, from Douglas College, 1981
BSN, from University of Victoria, 2003

Supervisory Committee

Dr. Laurene Sheilds, School of Nursing
Supervisor

Dr. Lucia Gamroth, School of Nursing
Departmental Member, Emeritus

Dr. Anne Bruce, School of Nursing
Departmental Member

Abstract

Supervisory Committee
Dr. Laurene Sheilds, School of Nursing
Supervisor
Dr. Lucia Gamroth, School of Nursing
Departmental Member, Emeritus
Dr. Anne Bruce, School of Nursing
Departmental Member

This study used narrative inquiry to answer the question "What are the stories of older adults who choose not to share information with health care professionals?" The study explored the experiences of older adults who did not share information with health care professionals (HCPs), who they defined as doctors. A thematic analysis of five participants' stories revealed three themes: *Illusions of Care*, describing the participants' experiences with doctors before they chose not to share information; *The Last Straw*, revealing the final incident that caused participants to choose not to share information; and *The Mask of the Non-sharing Older Adult*, describing how participants interacted with their doctors after they decided not to share information. Relationship development between older adults and their doctors, sensitive topics, issues and perceptions of ageing, and structure of the health care system contribute to the complex issue of older adults not sharing information. The decision not to share information with health care professionals may adversely affect the health and health care of older adults.

Table of Contents

List of Figures

Acknowledgments

I would like to express my deepest gratitude to the participants of this study, for without them there would be no research.

A heartfelt thanks to my thesis supervisor, Dr. Laurene Sheilds, for her guidance and support. A special thank you to my committee members, Dr. Lucia Gamroth, who started me on my journey, and Dr. Anne Bruce.

A special thanks to my mentor, Anne Earthy. Thank you to Marcia Carr for her passion and to Robyn Monrufet and Anne Gavey of Vancouver Island Health Authority for their support in completing my thesis. Thanks to Sue Parker for her transcribing.

Thank you to all those who supported me financially: Terence and Joan Brennan; Dr. Bryan Frazer; Kevin and Trish Brennan; Envision, Ladner Branch; the British Columbia Student Loan Service Bureau; and the National Student Loans Service Centre. Thank you to the Registered Nurses Foundation of British Columbia; Nurses Education Bursary Program; and the Dorothy Adams Bursary for awarding me funding.

A huge thank you to my parents, Terence and Joan Brennan, who provided me with their older adults' experiences and to my fabulous husband, Dr. Bryan Frazer, who lived through the writing of my thesis. Finally, thanks to family, friends, and co-workers, who always asked about my thesis – you know who you are.

Dedication

This thesis is dedicated to my parents, Terence and Joan Brennan. They know why.

Chapter 1 - Introduction

I inadvertently overheard a conversation while waiting in an ophthalmologist's office between an older adult woman, who was the client, and her daughter. The older woman had a procedure performed and was told to wait for 15 minutes before leaving. While waiting, she told her daughter that she was unable to see out of the treated eye. She went on to say that in the past when she had the same procedure performed on her other eye her vision was unaffected. The daughter asked her mother if she had told the doctor she could not see and the mother replied, "No. He didn't ask me." During further discussion, I heard the mother tell the daughter that the doctor asked if she was okay but not specifically if she could see, so she did not volunteer the information.

Many questions arose for me upon hearing this exchange. Did the older adult expect her physician to ask the *right* question and if so did this expectation apply to all health care professionals (HCPs)? Did she feel rushed? Did she believe her doctor was uninterested in her concerns? Was not sharing this information a one-time event or was not sharing common for her? Did she believe she was complaining if she said something? Was she raised to be stoic? I also wondered if she had known I was a nurse would she have been so vocal in the waiting room?

As these questions swirled in my mind, my curiosity peaked and I wanted to know more about older adults who choose not to share information with HCPs. Peer reviewed literature offered little in answering most of my questions. The phenomenon of older adults choosing not to share information with HCPs is understudied and the focus of this thesis. The issue of not sharing information with HCPs is often misunderstood and narrowly defined in the literature. Most researchers had a specific focus in their studies, such as the reasons for not taking asthma medications as prescribed (Malhotra, Karan, Pandhi & Jain, 2001; Playle & Keeley, 1998; Wroe, 2002) or the reasons for not disclosing symptoms or conditions of urinary incontinence (Dugan et al., 2001). While the research literature included studies about the perceptions and emotions of older adults (Dugan et al.) the findings usually were directly related to the specific condition studied. Within the literature, there is little if any, research that described the experiences of older adults who choose not to share information with HCPs.

Professional Perspective

Most HCPs I have spoken with about my interest in older adults responded with stories of their own experiences of discovering older adults not sharing information such as falls, past surgeries, forgetfulness, and pain. The responses of the HCPs were similar to mine and included: not understanding the reasons; feeling frustrated; experiencing the events as time consuming; and believing that older adults were placing themselves at risk.

Often HCPs assumed they *knew* why older adults did not share information. However, the factors for older adults not sharing information often differed from what HCPs believed or understood (Dugan et al., 2001; Playle & Keeley, 1998). A common assumption of the reason for older adults not sharing information is the fear of losing their independence related to ageing (Featherstone & Hepworth, 1991). Many of the HCPs that I spoke with had first hand experience with, or were aware of, literature that described the fear of older adults being placed in long-term care facilities as the primary reason for not sharing information (Dugan & Bonds, 2003; Featherstone & Hepworth).

The fear of being placed in a facility is a common concern among some older adults but other factors may have influenced older adults not sharing information with HCPs. I believe many HCPs have frequently categorized not sharing information into a single easily understood category, related to independence and autonomy, however the issue is far more complex. Older adults undoubtedly have stories that provide insights into their choices to share or not share information and illuminate some of the complexities of this experience.

Barriers for older adults to share information with HCPs may include uncomfortable relationships, the sensitive nature of some topics, misperceived perceptions of ageing, and obstacles within the medical model health care system itself. Stories of older adults choosing not to share information varied by reasons, degrees, and situations, which add to the complexity of the issue (Donovan & Blake, 1992). The rationale for not sharing information with HCPs does not stand alone; it is interwoven in a complex system of values, beliefs, and assumptions, creating responses unique to each older adult's experiences. Emotions, perceptions, and beliefs contributed to the decision of older adults choosing not to share information with HCPs (Donovan & Blake). Multi-layering of personal, situational, and cultural factors can create situations that are not straightforward or immediately understood.

The literature that is specific to older adults not sharing information with HCPs is at times contradictory (Malhotra et al., 2001; Wroe, 2002). Some researchers (Malhotra et al.) concluded the cost of prescriptions were a factor for not taking medications while other researchers (Wroe) discussed altering doses and forgetting to take medications were related to the belief of the medications effectiveness. Within the research literature, specific factors for older adults not sharing information with HCPs were studied (Greene, Adelman, Rizzo & Friedmann, 1994; Lau et al., 1996; Wroe), but few studies were done simply to listen to the stories of older adults (Donovan & Blake, 1992) who have chosen not to share information with HCPs.

This leads to the question: What is *relevant* information in understanding the phenomenon of older adults choosing not to share information and is it only HCPs who should define what is relevant? For some older adults, a belief that HCPs were not interested may have been a factor for not sharing information. A colleague complained to me that some older adults related every piece of personal and family information such as how grandma Ruby cured herself of gout with quince jam. In my experience as a nurse, I believe the stories of older adults, as much as they may sound insignificant to some HCPs, are attempts to build a foundation for a relationship, which consists of sharing stories that lead to understanding and knowing each other (Greene et al., 1994; Johnson, 1979).

Building strong client HCP relationships is increasingly difficult within the changing context of care. The replacement of Registered Nurses with clerical staff in physician offices has removed opportunities for nurse/client relationships. Shift work and lack of full-time positions in the health care system has created a lack of continuity of care for clients and nurses. Retirement of family doctors has left older adults without a primary physician, creating the need for developing new relationships with physicians who may have been the age of the older adults' grandchildren. Walk-in clinics, where older adults may have encountered a different physician on each visit, is yet another barrier to forming a relationship with a doctor.

Health care system issues founded in social policy have also created barriers for older adults. In British Columbia the constraint of discussing only one problem per physician visit has not been conducive to the development of a relationship between older adults and doctors or nurse practitioners. The practice of discussing one problem per visit have been even more problematic for older adults who are likely to have more than one chronic condition and are taking multiple medications (polypharmacy). It is common in British Columbia to wait weeks, if not months, for diagnostic procedures such as a MRI (Magnetic Resonance Imaging) and appointments with specialist practitioners (British Columbia Medical Association, News/Publications, Wait List Report II, n. d.). These waits are so common that it is now part of our social structure. The costs and co-payments of some medications and treatments have further affected older adults with lower incomes in British Columbia. The PharmaCare Plan of British Columbia has provided only partial or no coverage of some prescribed medications influencing older adults' choices regarding buying and taking prescribed medications. The Medical Services Plan pays only partial coverage of treatments such as chiropractic, massage therapy, naturopathy, physical therapy, and non-surgical podiatry (Government of British Columbia, Ministry of Health, Medical Services Plan, Medical and Health Care Benefits, n. d.).

Perceptions of ageing have been integral factors for older adults not sharing information with HCPs (Dugan & Bonds, 2003; Featherstone & Hepworth, 1991). The process of ageing is inevitable but has been viewed as an enemy by Western societal standards. These beliefs, interwoven with the social stigma and myths of ageing, may cause some older adults to have avoided sharing age related information with HCPs

(Moore, 1985). Age related perceptions have often been associated with falls, urinary incontinence, and failing eyesight to name a few. These perceptions are now an integral part of the history and culture of older adults (Ebersole, 2004). Therefore, beliefs about ageing have been a major factor in older adults choosing to share or not share information.

Perceptions that to be old is to be confused, sick, in pain, unsteady, asexual, demented, and ready to die along with the concurrent belief that nothing can be done about any of these conditions have led to not sharing (Cremin, 1992). It was discovered in Cremin’s study that self-referral to an outpatient geriatric assessment clinic was rare; rather clients were referred by concerned families. Perceptions of feeling old versus being old were differentiated within Cremin’s study. Older adults who did not feel old viewed their health concerns as temporary, therefore were less likely to seek help.

While some beliefs are gradually changing with the ageing of baby boomers (Ebersole, 2004), older adults have been trying to understand, not only their ageing, but also how to live in a rapidly changing technological and information-driven world. Cell phones, computers, and 1-800 health information lines have created a world of little personal contact for older adults. Older adults are more susceptible to increased stress from living in a technological advanced society (Hess & Ebersole, 2004) and may not share information with HCP because they perceive themselves as not being able to keep up with changes.

Choosing not to share information with HCPs has been an often-common belief of stoic older adults (Dugan & Bonds, 2003). My father, who is in his eighties, keeps reminding me that he was raised to be stoic. He has sometimes not shared information with HCPs because he has wanted to be perceived as strong. Stoicism is rooted in past and present experiences as well as future expectations. Not sharing information is embedded in the lives of older adults where values, beliefs, and assumptions may act as barriers.

The very nature of the personal and social aspects of older adults who have not shared information with HCPs leaves me with the desire to know and understand more. The importance of hearing the stories of older adults who have not shared some information with HCPs is vital to those who provide care and to the older adults themselves as a way of gaining more information about their care (Greene et al., 1994). Ageist attitudes are not limited to older adults but permeate the very fabric of our society. HCPs have been socialized within the same societal context and their perspectives may be mired with similar ageist beliefs.

Western medicine has thrived on treating disease and has often overlooked older adults' need for care rather than cure. Western society has viewed ageing as a condition to fight, especially in women (Feldman, 1999; Greene et al., 1994). These circumstances have resulted in double jeopardy situations for older adults where they were less likely to reveal changes they perceived to be associated with ageing. Some symptoms may be perceived as part of ageing (Hill & Luggen, 2004) and therefore not shared. HCPs may have be less attentive to these same conditions or have felt powerless to address issues that they believed are "a natural part of ageing" as many HCPs are steeped in the same societal beliefs. Moreover, even though attitudes are shifting, caring for older adults has not always been valued by all HCPs (Feldman). Ageist attitudes can take many forms such as tone of voice, choice of words, and jokes (Feldman) resulting in older adults choosing not to share information with HCPs who they believe or experience as being ageist.

Impact of Older Adults Not Sharing Information with Health Care Professionals

A concern about older adults not sharing information is that their reasons may be based on misconceptions or incorrect information and ultimately impact their quality of life and the quality of care they received. Older adults may be poorly informed about the impact of their decision not to share information. For example, simply feeling better prompted some older adults to reduce or stop taking their medications (Malhotra et al., 2001), which exacerbated their illness. Similarly, the belief that HCPs are too busy or not interested have lead some older adults to edit what they think HCPs may want to hear (Playle & Keeley, 1998) which has affected their quality of care.

The impact of not sharing information with HCPs is perhaps best explained through concrete examples which demonstrates the effect that not sharing information has had for some older adults. Urinary incontinence is a common occurrence in ageing and the leading cause of institutionalization of older adults (Hill & Luggen, 2004). The misconception that urinary incontinence is a symptom to live with, has led some older adults to not share this information which in turn resulted in serious health complications (Li, Guh, Lacaille, Esdaile, Anis, 2007; O'Hanlon & Coleman, 2004). Complications from untreated urinary incontinence may lead to urinary tract infections, disturbed sleep due to nighttime urination (Dugan et al., 2001), and increased risk for falls while attempting to get to the bathroom quickly. The older adults who have not divulged information about falling, have jeopardized themselves with possible hip or other fractures when perhaps the reasons for falling could have been easily addressed and treated (Dugan & Bonds, 2003). Surgery for fractured hips includes potential complications of infections and blood clots. Some older adults in long-term care facilities told me they had to go to a *home* because they fell, had surgery, and could no longer manage on their own, the very event that they were hoping to avoid by not sharing about their falls to their HCPs.

The nature of older adults not sharing information with HCPs is multifaceted in both cause and effect and the behaviours are not easily identified. Many older adults have appeared oblivious to the fact that not sharing information with HCPs may prolong their treatments and even jeopardize their lives. While caring for an older adult, my patient neglected to tell me, even though she had three opportunities, that she had a headache. She called for me just before the end of my shift to ask for medication. Because she was in discomfort and I was rushed to complete my duties, I asked only the basic questions. I would have been able to provide better care, instead of hurriedly giving her medication, had she chosen to share the information about her headache when it first occurred. When I asked her why she did not tell me earlier that she had a headache she said, “I did not want to bother you.”

The potential health care cost of older adults not sharing information has created a number of practice dilemmas for HCPs. When HCPs were unaware that medication and treatments were not followed as directed, additional medication and tests may have been ordered. The time used to order tests, prescribe new treatments, seek consultations and referral to specialists are labour intensive and have taken time away from other health care priorities. If there were more sharing of information, HCPs would be better able to determine the most effective, economical, and timely way to treat older adults (Playle & Keeley, 1998). Understanding the experiences of older adults has the potential to improve relationships between older adults and HCPs, ultimately providing for better care (Donovan & Blake, 1992).

Importance of the Study

The use of narrative inquiry to relate the stories of older adults provided a deeper understanding of the nature of not sharing information with HCPs. A greater understanding may lead to addressing the causes and increasing the quality of care that is also cost effective and timely.

This research explored the complexity of the issue of older adults choosing not to share information with HCPs. Rich stories demonstrated how not sharing information is part of a tapestry of values, beliefs, and assumptions of both older adults and HCPs. The intent to illuminate the personal and social components of the issue was a significant goal of this research. The method of narrative inquiry explicated stories, including the personal experiences, collective stories, and social aspects that have permeated the lives of the participants. This research has been directed toward taken-for-granted personal and social assumptions to expose the current gaps in knowledge of older adults who choose not to share information with HCPs.

The research provides HCPs with a better understanding of older adults who do not share information by exploring the multifaceted nature of this phenomenon. Appreciating the complexity of the issue will lead HCPs in providing better care for older adults through an improved understanding of those who choose not to share information.

The overarching purpose of this qualitative study was to explore the stories of older adults choosing not to share information with HCPs, which led to the research question, “What are the stories of older adults who choose not to share information with health care professionals?”

Definitions

Choosing Not To Share Information

It is essential to clearly define what ‘not to share information’ means. A synonym of sharing is defined by the dictionary as, “…having, using, or experiencing something with others…” (Brown, 1993) which includes information. I use the term ‘not sharing’ in contrast with some of the value laden terms such as non-compliance, nonadherence, and lying, which have often been used in the literature. Value laden terms implied wrong action on part of the clients and infer that clients have acted in ways that disobey the “orders” of a HCP. The approach of designating clients’ actions as wrong does not take into account the choices older adults make not to share with HCP and therefore have undervalued their experiences. The words ‘not sharing’ have best emphasized, in my view, that the decision not to share information is complex as it may include personal and social factors that are often not easily explained.

Older Adults

As people are living longer it is expected that those over 65 years of age will make up 24 percent of the total population in British Columbia, Canada by 2031 (Ministry of Health Services, 2004). As the population lives longer, older adults can live to over 100 years of age. Some researchers have used categories such as young-old (55 to 74 years) and old-old (75 years plus) (Fulks & Molinari, 1995; Ohio State University Extension, n. d.). Others have developed categories of 65 to 74, 75 to 84, and 85 years plus, labelling them as young-old, middle-old, and old-old respectively (Zauszniewski, 1996). There has been much disagreement between HCPs on these categories and the titles used, leading to confusion about what constitutes old age. There are also those who have defined age by health (Ebersole, 2004) and frailty (Mitnitski, Graham, Mogilner, & Rockwood, 2002).

To further confuse the definition of ‘old’, there is disagreement about when old age begins. Some studies identified ‘older’ as beginning at 65 years. Some senior discounts rates for goods and services begin as young as 50 years of age (Ebersole, 2004). Because of longer lives and better health it is becoming common to now define older adults as 70 or 75 years or older (O’Hanlon & Coleman, 2004).

Even though chronological age is now used less, it is still a generally accepted benchmark (Cremin, 1992) as qualification for government pension in Canada and socialized medical care in the United States is 65 years of age. For this study, I am using the age of 65 years as the beginning of older adulthood because it is the age in Canada for Old Age Pension (Health Canada, 2002) and Medicare in the United States (U.S. Social Security Administration, n. d.).

Summary

The nature of older adults choosing not to share information with HCPs is multifaceted. Current research has often focused on a specific health issue (e.g. urinary incontinence or falls). My perspective is that older adults have rich stories to tell which portray the complex tapestry of values and beliefs that underlie their choices in sharing or not sharing information with HCPs. This research intends to illuminate complex experiences of older adults who have chosen not to share information with HCPs, ultimately contributing to better care.

Chapter 2 – Literature Review

Introduction

Literature has mainly focused on reasons for older adults choosing not to share information with HCPs. For example, researchers have explored underlying rationale for factors such as medication non-adherence, urinary incontinence, and falls. Other researchers have explored relationships between clients and doctors as a factor in not sharing information and while not specific to older adults, these studies have proven to be useful context for this research. When current research did include first person stories of older adults, it usually related to specific factors, for example medication adherence, not the broader issue of not sharing information. This research explored the experiences of older adults who choose not to share information with HCPs and the complex interplay of personal and social values and experiences.

To better understand the state of the literature I created a conceptual framework to describe how researchers have discussed the concepts related to older adults choosing not to share information with HCPs (Figure 2.1). The larger inner nucleus shows older adults choosing not to share information with HCPs. The four surrounding concepts of: relationships with HCPs; sensitive topics; issues and perceptions of ageing; and the structure of the health care system lead to the nucleus of older adults not sharing information with HCPs. The conceptual framework was developed based on the existing literature; therefore, the experiences of these older adults are not included in this framework because there is little literature that refers to their experiences. The arrows pointing from the concepts to the nucleus represent findings in the literature that have indicated a one-way flow where the concepts are the identified reasons for older adults not sharing information with HCPs.

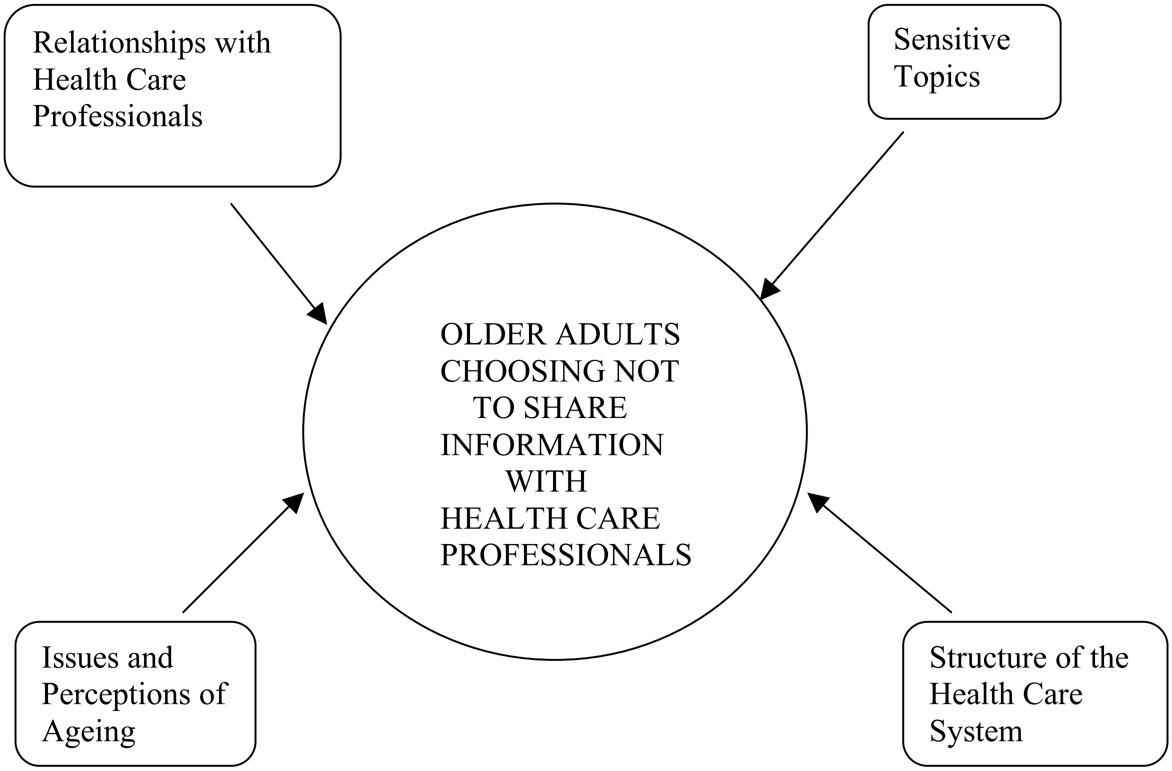


Figure 2.1. Concepts in the literature that impact older adults' choosing not to share information with health care professionals

Not Sharing Information with Health Care Professionals

Research showed that people of all ages choose not to share information with HCPs (Bok, 1989; Bok, 1999; Jourard, 1971; Lau et al., 1996; Malhotra et al., 2001; Saarni & Lewis, 1993; Wroe, 2002). The various reasons for not sharing information have created an abundance of definitions of the issue.

Many authors used the words ‘non-compliance’, which is defined as “…in the presence of an agreed-upon health-promoting or therapeutic plan, person’s or caregiver’s behaviour is fully or partially adherent or non-adherent and may lead to clinically ineffective, partially effective outcomes” (Venes, 2001). The definition of non-compliance varied in degrees from those who do not comply, partially comply, under-use, and over-use treatment or prescriptions (Playle & Keeley, 1998).

The term non-compliance is often used in reference to not taking medications as prescribed (Lau et al., 1996; Malhotra et al., 2001). Some factors that impacted older adults intentionally not taking medications included the cost, unwanted side effects, switching to non-traditional medications (Malhotra et al.), misunderstanding the purpose of a medication, polypharmacy, and the type of prescriber (e.g. general practitioner or specialist) (Lau et al.). Wroe (2002), studied participants of all ages with respiratory conditions who did not share the fact that they did not always take their medications. Wroe used the words ‘intentional nonadherence’ and stated that clients made a choice to not take their medications.

Donovan and Blake (1992) included personal and social circumstances in their study of the reasons why some older adults did not always take their medications. The authors discussed that older adults were embarrassed to divulge to their HCPs that they were unable to afford the medications. The sensitive nature of their finances influenced their decision not to share. The personal issue of finances colliding with the societal issue of limited or no pharmacy coverage created a situation where older adults did not share information with HCPs. Donovan and Blake emphasized the reason for not sharing information is often overlooked. First person stories about not sharing information would include thoughts and feelings as well as contextual factors, however this is rarely studied. In other words, the thoughts, feelings, and perspectives of older adults are simply ignored. There is little examination of the factors that influenced older adults decisions to not follow HCPs' orders or advice.

Bok (1999) described not sharing information in the context of telling the truth and lying. In her work, she discussed the effects of not telling the truth. Bok suggested that those who do not tell the truth cautiously viewed those they lied to, creating a barrier in a relationship. She also wrote that one lie may lead to another. It is common knowledge that a person may continue to lie to cover up an original lie. In 1908, Sir Walter Scott penned the fitting words, "Oh what a tangled web we weave, when first we practice to deceive!" which is still commonly quoted one hundred years later. Bok's work suggested that lying is more likely to occur in the absence of a trusting relationship. Jourard (1971), a psychologist, described a factor of not sharing information as non-self-disclosure within the context of the development of a therapeutic relationship. Self-disclosure is a concept common to the discipline of psychology but Jourard suggested that all HCPs must self-disclose to receive self-disclosure in return. While non-disclosure and lying are conceptually different from the central focus of this study on older adults, Jourard, Bok, and Scott have demonstrated that not sharing information is a complex issue.

Regardless of the terms used in the literature, I find that older adults who choose not to share information with HCPs are poorly understood. Donovan's and Blake's (1992) study suggested that older adults "…crave more information about their disease and treatment…" (p. 512) which is often not forthcoming from HCPs. A strained relationship between older adults and HCPs promotes not sharing information by older adults (Donovan & Blake).

Relationships between Older Adults and Health Care Professionals

There was much written about relationships between clients of all ages and HCPs. Jourard's (1971) work, while from the seventies, is timeless as he supported the claim that decisions to not share information are based upon the manner in which HCPs treat clients. Jourard described the importance of professionals addressing the experience of clients:

> Hence, many behavioral scientists ignore man's "self" – his experience of his situation-since it is essentially a private phenomenon. Others, however, are not so quick to allocate man's self to the limbo of unimportant, and they insist that we cannot understand man and his lot until we take his experience into account (p. 26).

Jourard studied the relationship between student nurses and hospitalized clients, finding that students who revealed more information about themselves to their families and peers were more open with their clients. The 'open' students created a caring relationship that facilitated clients disclosing more information confirming Jourard's theory that "…disclosure begets disclosure" (p. 66).

Some studies addressed the link between clients' stress levels and choosing not to share information with HCPs (Greene et al., 1994; Johnson, 1979). These studies found that not sharing information increased as stress levels and anxiety increased. It could be suggested that client centered models of care as contrasted with medical focused problem-based models of care facilitated better relationships between older adults and HCPs, resulting in decreased stress and anxiety, thus increasing sharing of information.

Sensitive Topics

The effects of ageing can be particularly sensitive for many older adults (Featherstone & Hepworth, 1991) and result in older adults not sharing information with HCPs (Dugan & Bonds, 2003) and families. Sensitive topics directly related to underlying values, beliefs, and assumptions therefore vary from person to person and from generation to generation. Topics sensitive in nature for one person may not be sensitive for another person, creating uniquely individualized reasons for not sharing information. Coupland, Coupland, Giles, Henwood, and Wiemann (1988) discussed that topics deemed sensitive to older adults differ from that of younger adults, implying that the information that older adults may not share can differ from that of other age groups.

Sensitive topics are attached to strong emotions and the stronger the emotion the more likely a person will not share the information (Saarni & Lewis, 1993). Sensitive topics were unlikely to be discussed with physicians by clients of all ages (Bok, 1989; Coupland et al., 1988; Dugan et al., 2001; Greene et al., 1994). Greene et al. found that 40% of their participants disclosed no intimate content to their physicians. Coupland's et al. study focused on how emotionally painful self-disclosure could not adequately be studied using quantitative means, confirming the need to use a qualitative method to study the issue of older adults not sharing information with HCPs. Dugan et al., in their study on the reasons why older adults choose not to share information about urinary incontinence with their doctors, discussed that a common concern was the sensitive and embarrassing nature of urinary incontinence. To further complicate the issue, Dugan et al. found that unless specifically asked about urinary incontinence, older adults were not inclined to initiate the discussion. Ageing can often bring about changes that may be sensitive in nature, which would make it more likely for older adults not to share information with HCPs.

There is abundant literature about older adults that focused on specific topics such as, mental health, alcohol and drug misuse, and sexuality. Within the literature there are discussions about the degrees of stigma attached to these topics and each of these issues are identified as sensitive in nature thus influencing what information older adults do not share. While reviewing issue specific topics is beyond the scope of this study, it is important to note the literature is consistent in describing the sensitive nature of issues and the degree of stigma attached as being directly related to not sharing information with HCPs.

Issues and Perceptions of Ageing

Hess (2004) states that we are unable to be objective about ageing because we are also experiencing ageing, but for some, our curiosity about life experiences of older adults creates an interest in research (Hess; Russell, 2007). The field of gerontology is growing but many nurses and other HCPs did not begin by specializing in this area, rather they discovered gerontology through job availability (Ebersole, 2004). Gerontology is still not included in the nine specialty nursing certificates and degree programs offered at the British Columbia Institute of Technology (n. d.). While it could be argued that gerontology is integral to the preparation of all nurses, it is important to understand ageing as a phenomenon that we each experience.

There is little literature on development phases of older adults (Hess, 2004), which could differentiate the decades. Each adult decade is individually addressed up to the sixties but after the sixties older adults are often simply lumped together in a group that included an age span of over 40 years (Ebersole, 2004). Some studies of older adults did not consider the differences between 65 years olds and 105 years olds adding to the misconceptions of older adults (Ebersole).

Ageing is seen as a social phenomenon, where some societies are unprepared to allow older adults to remain in meaningful roles, especially those roles with power and prestige (Hess, 2004). This phenomenon is apparent in countries with a mandatory retirement age, where retiring is based on age, not skill or desire. It is only in the past five years that many of the Canadian provinces have banned mandatory retirement. The 65-year-old mandatory age of retirement in British Columbia, Canada was eliminated in 2008 (British Columbia, Ministry of Attorney General, n. d.). Older adults can now work past the age of 65 years, where previously the government deemed them as unfit to work because of their age. These changes, while slow in coming, are indicative of societal perceptions of ageing and the capacities of older adults ability to work, however societal perceptions of the capabilities of older adults making decisions related to their health is still an issue.

In their earlier work, Rowe and Kahn (1987) found that it was common to treat ageing as a factor for ill health. It is common for some older adults to experience health challenges as they age, as chronic diseases tend to multiply as ageing occurs (Hill & Luggen, 2004). Unfortunately, many older adults have been told to live with chronic illnesses with little support of how to manage activities of daily living, which contributed to the perception that to be old is to be disabled or in pain. The perception "to be old is to be sick" has permeated society and may have led older adults to believe that chronic illnesses are part of getting old. Chronic diseases then, have infringed on quality of life creating dependency, which may further led to older adults not sharing information with HCPs.

In their later work, Rowe and Kahn (1997) found a shift in understanding ageing where successful ageing included avoiding disease and disability, engaging with life, and maintaining cognitive and physical functions. Hess and Ebersole (2004) stated the goal for healthy ageing "…is to delay illness, prevent the ill from becoming disabled, and assist those who are disabled to function and prevent further disability" (p. 57). Successful ageing is not the absence of disease or disability; it is living life to the fullest regardless of disease or disability. Unfortunately, Western society still views ageing as a disease. Older adults may have not shared their feelings, motives, attitudes, and beliefs as a strategy to mask what they perceive as *getting old.* Featherstone and Hepworth (1991) called not sharing information about ageing the "mask of ageing" (p. 371).

Because older adults are less valued in Western society, they often do not share information about their loss of independence (Featherstone & Hepworth, 1991; Moore, 1985; Stephens, 1976). Older adults who choose not to share information often want to avoid the social stigma of being viewed as old. The fear of being sent to live in a facility or with family is often a concern for older adults, which may have led to not sharing about their decreasing independence. To assume though that not sharing information relates entirely to hiding the effects of ageing devalues older adults' decisions not to share information with HCPs and their reasons for doing so. To keep ageing in perspective, HCPs must not make common what is not common (Featherstone & Hepworth), such as Western society's erroneous belief that ageing is a disease.

Dugan and Bonds (2003), in a fictional case study, described that not sharing about falls is common yet the very lack of information itself threatened older adults' independence. Hearing about falls is exactly what HCPs expected and needed to hear (Dugan & Bonds). Falls are related to a myriad of problems such as the environment, individual factors, and treatment factors, (Luggen & Hill, 2004). A perception that telling HCPs about falling could result in being placed in a facility is not without merit as almost half of older adults who fell are eventually admitted to care facilities (Luggen & Hill). Loss of dependence is a factor for older adults not sharing information with HCPs.

Structure of the Health Care System

The British Columbia health care system promotes cure rather than care and this Western concept creates a social barrier for older adults. Western society treats older adults as if they are decaying instead of just ageing. Older adults often receive limited care because the British Columbia Medical Services Plan pays physicians and nurse practitioners for one medical issue per office visit. This means that older adults must make a second appointment if they have two health care concerns to discuss. Older adults are more likely to suffer from more that one chronic illness, which creates complex health issues. Having different appointments for various health issues is a barrier to care.

Older adults are often rushed during physician visits, as it is common for physicians to see two clients every 15 minutes. A holistic approach is required to care for older adults, who often have chronic multiple health issues and polypharmacy, but the British Columbia Medical Services Plan does not support this type of approach. With the creation of walk-in clinics in British Columbia, provision for continuity of physician care has decreased. Clients may see a different doctor every visit and there is simply no time in a seven-minute appointment for a doctor to review a clients' file. Clients must be very efficient in relating the reasons for their visits. The lack of continuity is not conducive to care, especially for older adults who have a higher incidence of chronic diseases. "The current health care system is not linked to community resources in a way that supports health improvement for the majority of the population" (Government of British Columbia, Ministry of Health, Medical Services Plan of British Columbia, Legislation and Governance of the Medical Services Plan, n. d.) leading to further isolation of older adults.

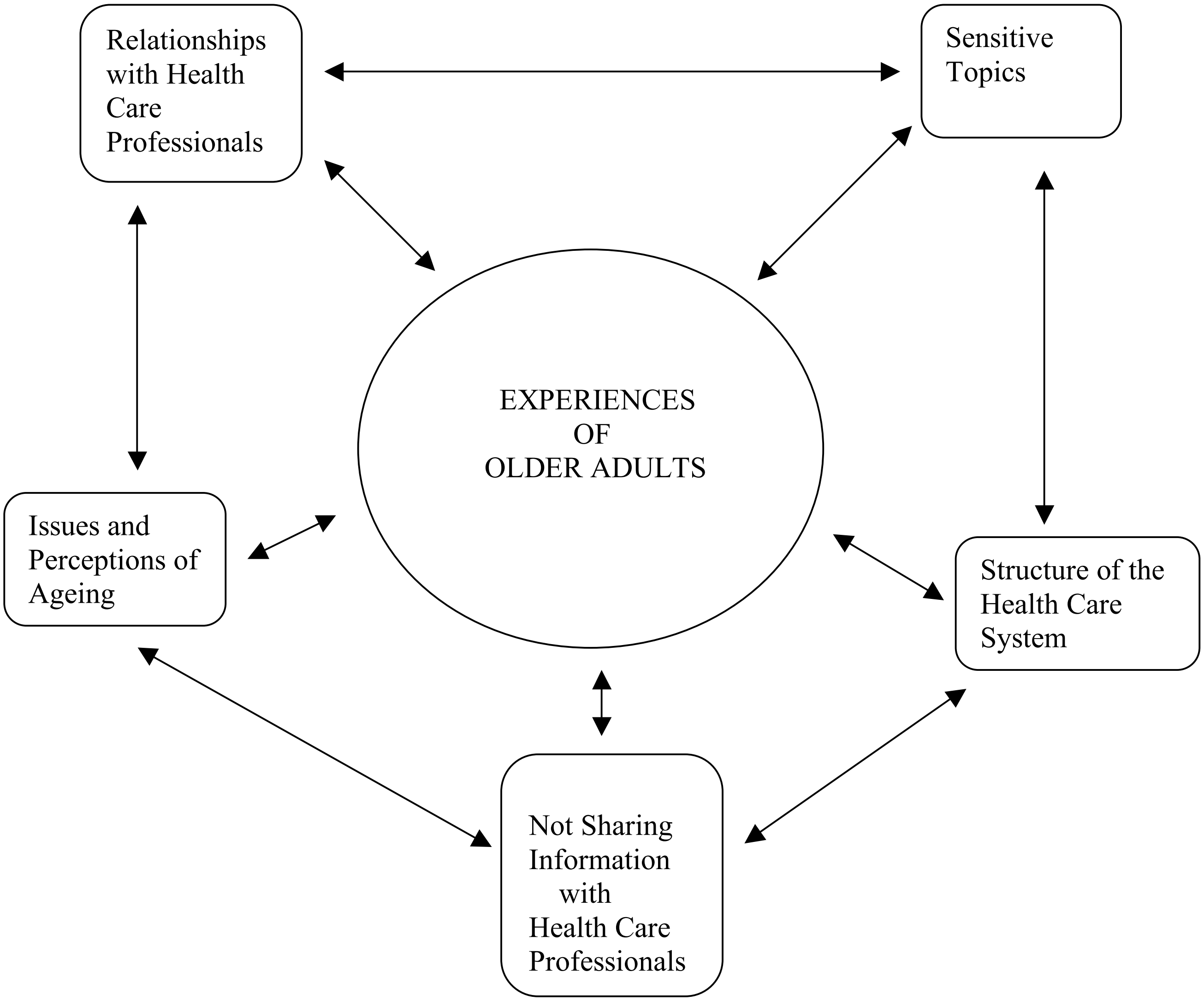
In British Columbia, older adults have a pharmacy co-payment with the PharmaCare Plan. When pharmacy cost sharing increased in British Columbia it was observed that a decrease in prescription filling occurred leading to a discussion if older adults switched to cheaper over-the-counter substitutes (Li et al., 2007). These authors also found that clients who did not fill their prescriptions because of the cost, visited their doctors more often, concluding that office visits were used as a substitute for unaffordable prescriptions.

When some older adults are dying, it is commonly heard that they are old so it is expected, as if one is dying from being old instead of a disease or condition. The need for end-of-life care for older adults is often overlooked (Black, 2007). Because of this, palliative services have not always been offered to older adults.

Summary

Both personal and social factors have driven the phenomenon of older adults not sharing information with HCPs. The choice to not share information has often been an uneasy one to make. The dictionary defines ‘preference’, a synonym of choice, “…indicates choice is based on one’s values, bias, or predilections” (Morris, 1975), confirming the complexity of older adults choosing not to share information with HCPs.

In this study, I explored first person stories of older adults who chose not to share information with HCPs to increase the depth of understanding about all older adults. The conceptual framework demonstrates the location of this narrative inquiry with the experiences of older adults as the central concept (Figure 2.2). The older adults’ experiences are at the nexus of the concepts of: not sharing information with HCPs; relationship with HCPs; sensitive topics; issues and perceptions of ageing; and the structure of the health care system. The scarcity of literature about older adults choosing not to share information with HCPs confirmed the need for this research.



(arrows represent reciprocal flows between the concepts and older adults)

Figure 2.2. The experiences of older adults as the central concept

Chapter 3 – Methodology

When stories are not told, we risk losing our way.
Ann-Marie MacDonald, The Way The Crow Flies

Narrative Inquiry

The very nature of older adults choosing not to share information with HCPs lives within their stories. Storytelling is not free-floating, but securely fixed in the world of storytellers (Frid, Öhlén, Bergbom, 2000). The retelling of stories have provided healing through insights, leading to new worldviews that changed future experiences of storytellers (Riessman, 2008) as people made sense of their world through storytelling. It is these stories that interest narrative inquiry researchers.

The interpretive drive of narrative inquiry is to understand the experience of a storyteller (Riessman, 2008) and is ideally suited to answering my question, “What are the stories of older adults who choose not to share information with health care professionals?” Narrative inquiry is not simply a repetition of participants’ stories; it is the art of telling the stories of others with authentic interpretations by creating meaningful patterns in the form of a story from what may first appear as a random series of events (Riessman). The art of narrative inquiry is embedded in the researchers’ understanding of the experiences of storytellers. Narrative inquiry is a written representation of the spoken word, with researchers and storytellers involved in the creation (Riessman).

Riessman’s (2008) approach to narrative inquiry guided me to recount the experiences of the participants. The approach was a journey into the unknown, but that was part of the process. I looked beyond the words of the participants to their experiences and then put those experiences into written word. I created meaning within the seemingly randomness of the content yet hopefully stayed true to the experiences of the participants. Riessman's thematic analysis of narrative inquiry focuses on the story as a way to present theoretical claims. While language may be ambiguous, researchers are encouraged to look beyond the words (Riessman).

Locating Myself

Banister (1999) pointed out that narrative inquiry is a process of self-discovery for the researcher. I am interested in older adults who have chosen not to share information with HCPs, to not only learn about older adults experiences and choices, but also to learn about myself as a nurse and as a person who is ageing.

In undertaking the preparatory work for this study, I became aware that I have not shared information with a nurse, a dentist, and a doctor. I blatantly did not reveal my weight by giving an incorrect number to a nurse. I did not tell my dentist I was taking over-the-counter herbal remedies. I did not tell my doctor I was under chiropractic care. I intentionally chose not to share information with these HCPs. This awareness of not having shared information with HCPs did not emerge until I started this research. I find that explaining why I choose not to share information is not easy, as I am nervous about being misunderstood and judged. My nervousness signals to me that the process of not sharing information with my HCPs is much deeper and complex than simply not sharing a piece of information. My choices have many dimensions. My experiences affect my choice and these experiences are embedded within my own story.

Reflexivity involved critical reflection throughout the research process (Guillemin & Gillam, 2004) and evolves as the research progresses (Banister, 1999). Reflexivity guided my approach to the research by fostering openness, encouraging me to be willing to suspend belief, and facilitating the questioning of my assumptions. When researchers go on a journey with the storyteller, reflexivity is attained by active listening, responsive journaling, and debriefing. Reflexivity in active listening means responding appropriately to participants as they tell their stories (Guillemin & Gillam, 2004). Active listening during interviews occurs in the form of not interrupting, acknowledging participants' experiences, and using silence as participants work through their emotions. It is not necessarily the wording of the questions, but the emotional engagement and reciprocity in the conversation that creates active listening (Riessman, 2008). Active listening facilitates trusting relationships with participants which then can elicit rich descriptions. I attended to each of these attributes of active listening.

Reflexivity in journaling is a process that exposed my taken-for-granted beliefs (Polit & Beck, 2004). I began writing reflectively before I started my proposal for this study, which created an awareness of my assumptions (Banister, 1999). I approached journaling as an active process where I was encouraged to not simply observe, but embrace my lived experience and explore how I interpret the experiences of others (van Manen, 1997). Through the process, I discovered that I am sometimes impatient with those who do not share information. I do not fully understand the often-sensitive topics of urinary incontinence or financial status because presently they are not issues for me. If they were issues for me, I may indeed find the topics sensitive.

Reflective journaling provided an opportunity to record my experiences and feelings when I interacted with participants. My reflections were written after telephone calls and interviews. I also included participants' tone of voice and body language during the interviews in my journal. After the interviews were transcribed, I noted the information from my journal into the corresponding margins of the transcripts.

As a nurse, my feelings are mixed when older adults have chosen not to share information with me. When the complete information finally emerged, I found it frustrating and time consuming to re-assess, re-diagnosis, re-plan, re-implement, and re-evaluate care. I wanted to provide quality care to older adults but worry that I could be potentially harming them if they have not shared some information. After I discovered that an older adult had not shared information with me, I wondered every time we talked if they were again not sharing information, which negatively affected our relationship, because I felt distrustful. Yet, I also believed that older adults were entitled to make their own choices, including not sharing information with HCPs.

Debriefing with my supervisor after the interviews provided insights and useful feedback. Debriefing, as with journaling, created opportunities to expose any biases and explore aspects of the research that I may have overlooked (Polit & Beck, 2004). Debriefing occurred as soon as possible after an interview to assist in exposing any such biases.

Participants and Recruitment

Participants recruited were adults over 65 years of age, who self-identified as having chosen not to share information with HCPs in the past five years. Selected participants were able to clearly articulate their experience in English.

A paid advertisement announcing my need for participants ran for one printing in The News, a local newspaper (see Appendix A for Advertisement). The advertisement contained my name and for confidentiality, my cell phone number. I received one response from the advertisement, but the potential participant eventually declined to participate because of ill health. Because only one response was generated and the advertisement was costly, I decided not to advertise again in the other local newspaper.

I placed 8.5 x 11 inch posters in the two local public libraries and a seniors' drop in centre. Attempts were made to place posters in other centres but for various reasons, such as limited wall space and supervisors on vacation, they were delivered but were not posted. The posters generated one response. News about my research was also spread by word of mouth as various people asked me about my study, for example when I was grocery shopping.

I modified the wording on the posters (see Appendix A.1 for Advertisement). I asked one of the libraries to place the poster in a more central location. I also asked a reporter at The News if she would like to interview me as a local interest story and she agreed. I used care in answering the reporter's questions and kept my request for participants as the focus. Ten days later, I was profiled in the newspaper. I received six phone calls within five days. All participants that telephoned were over 65 years of age but two did not fit the criteria of not sharing information with HCPs. Four participants were generated from the newspaper article. One participant expressed interest through discussion of my research in a social situation and telephoned after reading about my research in the newspaper article, resulting in five participants for this study.

The newspaper article generated a telephone call from a local non-profit community organization to be a guest speaker at a weekly seniors' group. Approximately 40 seniors met my speaking engagement with enthusiasm. I discussed my research, passed out posters, and asked for those who fit the criteria to telephone me, but I did not receive any telephone calls. Participant recruitment started March 24, 2008 with the newspaper advertisement and was completed on June 11, 2008, when I presented my research to the seniors' group.

Asking older adults to *share what they did not share*, was asking participants to expose themselves, which may have hindered recruitment. Living in a small rural area, where others often know more personal information than many would want, may have also been a challenge to my recruitment. Even though I stressed confidentiality and the use of aliases, there may have been fear of exposure. I also live in the area so participants and I may eventually meet at functions or in restaurants, which could have caused some of them embarrassment by seeing me socially.

Initial Telephone Contact

I explained the nature of the study to potential participants when they telephoned. I informed them the study was confidential and I described the benefits, inconveniences, and potential risks. I read the list of questions that I might ask during the interview (see Appendix B for Questions). I provided time for potential participants to ask questions.

Recognizing that the initial telephone conversation was the beginning of a relationship, I asked if the study interested them enough to continue and they all agreed. I took names and numbers and I telephoned the participants a few days later to arrange a day, time, and location for the interviews.

Interviews

As a result of being profiled in the newspaper, I found people recognized me on the street and confidentiality of participants could have been compromised if I met them in a public location, so I was cautious where interviews took place. Three interviews took place in the homes of participants, one interview took place in a private business office, and the fifth interview occurred in my home. The participants determined all the locations. To prepare for the interview in my home, my spouse left 30 minutes before the interview was to begin. When the participant arrived, we spent some time with my dogs so they would not bother us during the interview and I turned off the telephone ringers.

Success of the interviews depended on the quality of relationships between the participants and myself. I began by asking about information I learned during the telephone conversations, such as names of pets, which achieved a relaxed atmosphere. When the potential participant was comfortable, I read the consent form (see Appendix C for Participant Consent Form) aloud as they looked at their copy. I then asked the participants to read the form and allowed time for questions. The name and telephone number of a support person was obtained and the reason for having a support person was explained. Participants signed two identical Participant Consent Forms. One copy for was them and one copy was for me.

I became more comfortable and adept at interviewing with each participant. I allowed the first participant to essentially control the flow of the interview, but by the last interview, I was able to easily keep the interview focused on my research question by ensuring that the participant fully understood the focus of the research. Three participants shared specific events that they believed were relevant to the research, for example a relative's medical condition. I explained that I was interested in hearing what they had to say and suggested that we could talk after the interview. As I developed confidence, I became more proficient at redirecting the interviews back to the focus of my research by saying, "I'm interested in what you said earlier" or "Can you please tell me more about that?" or "What was that like for you?"

During the interviews, I used semi-structured open-ended questions to facilitate rich narrative responses (see Appendix B for Questions). Each interview lasted between 40 to 50 minutes. The participants did not become distressed so no support persons were called. After each interview, I thanked the participants and reminded them to call me if they had any further questions or concerns.

Data Collection

Data collection was achieved by audio recordings. I used a digital voice recorder and an audiocassette recorder simultaneously to prevent loss of data should one recorder have malfunctioned. I carried extra batteries and audiocassettes tapes.

A paid transcriptionist transcribed the recordings. I checked the accuracy of the transcription by listening to each taped interview while reading the hard copy. Even though narrative inquiry looks beyond what is said, verbatim transcription was essential for accurate analysis. I gave aliases to each participant to protect their confidentiality.

Participant Withdrawal

There was no compensation for participating in this study. Participants were informed of the right to withdraw from the study during the initial telephone conversation and during the signing of the Participant Consent Form (see Appendix C for Participant Consent Form). Although participants had the right to withdraw at any time and were not required to disclose a reason, no participant withdrew from the study. If a participant had requested to withdraw, I would have asked if their data could be have been used in the study. If a participant was willing to have their data included, written consent to use data after withdrawal would have been obtained (see Appendix D for Consent to Use Data After Participant Withdrawal Form). If a participant would have decided not to have their data used, their data would have been destroyed and no further contact made.

Inconvenience and Risks to Participants

One inconvenience to participants was the use of their time and home for those who offered their homes for interviews. The other two participants drove to their interviews. Another inconvenience was that storytelling may be tiring, but no participants required a rest break. Storytelling may create embarrassment or participants could have become upset by their insights, but this did not occur.

Confidentiality

The names of the participants in this study are confidential. Personal information was removed from the transcripts and aliases were used to identify participants. All audiotapes and information on paper were stored in a locked filing cabinet in my home. Information in computer files was protected by passwords. Consent forms and alias information were stored in my home in a separate locked filing cabinet from the interview data. All paper, except transcribed data, have been shredded, audiotapes have been be erased, and computer files have been deleted. The transcribed data will be kept for purposes of possible secondary analysis for five years then shredded.

Ethical Considerations

I worked as an RN in a local facility that provided assisted living and complex care needs to older adults. I also taught a clinical component of a Residential Home Care Attendant program for a local college at the facility where I worked and two other local complex care facilities. I included my name in the advertising so if there were previous relationships with potential participants they would be aware who they were telephoning. I had no previous professional relationship with any participants. Socially, I had met one participant at a function. As previously stated my cell phone number was used, as I was the only person with access to that phone. During the initial conversation, I explained that participation in the research was voluntary and non-compensatory and I read the list of questions that I might ask during the interview (see Appendix B for Questions).

The reasons for doing my research were stated honestly and respectfully to all involved. Clinical interventions are more common with researchers who are also nurses known to participants in a professional capacity which can create a common ethical dilemma among qualitative nurse researchers (Holloway & Wheeler, 1995; Wilkes, Cert, & Beale, 2005). Even though I had no previous professional relationship with the participants, I was prepared to provide some clinical intervention, but none was required.

I was under an obligation, as a Registered Nurse, to report any abuse to or by participants (CNA, 2002). Reporting such abuse would have been the only time I would have broken confidentiality and this was explained before potential participants become participants (see Appendix C for Participant Consent Form). If abuse had been reported to me, which it was not, I would have explained to the participant the need to report the information to the appropriate authority. Depending on the situation, I would have either reported the abuse with the participant present or after I left the interview. The University of Victoria Human Research Ethics Board approved this study.

Thematic Analysis of Narrative Inquiry

Following Riessman's (2008) approach, I began by exploring individual participants' stories. From my journal, I added my observations of body language, voice tone, and impressions at the time of the interviews to the margins of transcripts. The technique allowed for the content of the interviews to be more than the spoken or written words. I also discussed my interpretations with my supervisor who assisted in my analysis.

I used an approach of highlighting text to identify participants' experiences and decisions. As I sat with highlighter in hand, I was unsure where I was going. I was initially led to the point when the participants decided not to share information with their

HCPs so I began highlighting words and phrases that addressed that event. After highlighting the event for all the participants, I proceeded to highlight, using a different color, the text describing the experiences that occurred before the decision not to share information was made. I then highlighted, in a third color, the experiences of participants after they decided not to share information. In this way, temporality was used as a lens of analysis (prior to the event, the event, and after the event).

After all the participants' text were highlighted for the three experiences, I compared the text between participants. I then reread the transcripts numerous times focusing on each word and phrase, regardless of the highlighting, asking if my research question was answered. From these readings I cross-referenced words and phrases between participants, which guided me to similarities and differences between participants. Three themes were identified: the experiences of participants before they decided not to share information; the time when they decided not to share information; and interacting with HCPs while not sharing information.

Validity and Trustworthiness

Sample size and saturation are common considerations in some qualitative research, but narrative inquiry has no such considerations (Polit & Beck, 2004). The key components determining narrative inquiry following Riessman (2008) are validity and trustworthiness. Narrative inquiry requires two levels of validity, the stories told by participants and the trustworthiness of the analysis (Riessman). Analysis is not an objective process, but rather an engagement by the researcher where validity is assessed from the perspective of the researcher.

Narrative inquiry is the art of telling a participant's story by not following rigid criteria because rigid criteria can "…simplify what are complex validation and ethical issues…" (Riessman, 2008, p. 185). Validation in narrative inquiry is not in finding the absolute truth but rather what is true to the storyteller and researcher (Riessman).

Readers may ask the question, "Why should I believe this writer?" Storytelling by older adults is a form of communication, where I focused on the themes that allowed me to relate their stories. Trustworthiness is created by remaining authentic to the stories told (Riessman, 2008). Following the methodology described above demonstrates trustworthiness through my interpretations of the data. Authenticity creates validity because it is true to the process.

Summary

Narrative inquiry, being a dynamic process where participants share stories of their experiences, is also suited for researchers to engage as co-participants in developing narrative and meaning (Riessman, 2008). Narrative inquiry is the art of telling the stories of others, which guides readers to an understanding of the storytellers' experiences. As a method, narrative inquiry, best answers my question, "What are stories of older adults who choose not to share information with HCPs?"

Chapter 4 – Findings

Introduction

This narrative inquiry research included five participants who chose not to share information with their doctors. All the participants were self-referred and lived in a small community. Three participants were widowed and two were married. There were four females and one male. Four had children and grandchildren. Their ages ranged from 65 to 89 years. Four participants were retired professionals, three from health and social service sectors. All participants had hobbies outside of the home.

It is common in narrative inquiry to begin the findings by describing individual participants. I did not write individual stories to maintain confidentiality because of the small geographical area we live in. Instead, I created a ‘composite participant’ to provide a flavour of the interviews and to aid in appreciation of the richness of the information revealed by the participants yet retained confidentiality.

The Composite Story of Chris

I named this composite Chris, a female, because four of five participants were female. Chris is 77 years old, living alone in her own home after the death of her spouse. She has children and grandchildren with whom she is in contact, but they do not live in the same community as her. Chris is a retired teacher with hobbies, such as bridge and gardening. Watching the health care system decline throughout the years has created frustration for Chris and she has some specific ideas on what should change. When she spoke about the problems of health care system and the impact on her family, friends, and herself, she became very animated.

Chris is on daily medication for rheumatoid arthritis (RA). She shared with me that she sometimes has pain, but that she no longer shares this information with her doctor, as he has ignored her when she has told him in the past. She asked for a specialist referral, which her doctor kept putting off for reasons she does not fully understand. Chris sees her doctor every three months for a prescription renewal, but no longer initiates any verbal interaction with her doctor. She returns to her doctor for the prescription renewal because she believes that the medication she is taking is beneficial for her health, otherwise she would not return to her doctor at all.

Chris researched the Internet and believes she fully understands the use of supplements that aide in managing the pain of RA. When she presented the information to her doctor, he refused to read the research and threw the papers on the table saying that he did not believe in “that stuff.” Chris decided to take supplements and not tell her doctor. Chris recently began seeing a naturopath physician. After experiencing her doctor’s behaviour, that Chris called unprofessional, she has decided not to tell her doctor that she is seeing a naturopath. Chris is not sharing this information with her doctor because she is concerned her doctor may tell her he will not care for her anymore. She is not concerned about going to another doctor; rather her concern is that there is a shortage of doctors in the community.

Chris did not refer to herself as old during our interview, but rather as a person who is doing her best to take care of herself. She presented as a strong minded and independent woman. Had I only read the transcript of her story and not seen her, I would not have known she was an older adult.

Chris was very adamant that her confidentiality be maintained for her to participant in this research. She did not want her friends or her doctor to know that she did not share information with her doctor. She was hesitant to share that she did not share, but she decided to tell me because she needed someone who would listen. At the end of the interview, Chris told me she felt better that she got her not sharing about not sharing "off her chest."

Participants

Each participant had a specific story they wanted to tell, that appeared to be the central reason for their willingness to participate. Choosing not to share information with their HCPs was present in each story, but the stories differed significantly in content. Stories included a sudden death of a spouse, alcoholism, perceived dislike by a doctor, a general lack of trust in doctors, and frustration with the structure of the health care system. The diversity among the participants was evident as one participant was very forthcoming in relating why they chose not to share information, while another participant stated they *did* share information with their HCP, yet they told of times when they *did not* share information.

Participants differed in their levels of confidence when talking with their HCPs. One participant was proactively verbal with the HCP which resulted in receiving care that she believed was best for her. Another participant was less talkative with his HCP, but equally proactive in finding the care he wanted by including alternative practitioners. At the other end of the spectrum was a participant who was quiet and passive with her HCP, which appeared to result in her receiving care that was less than she desired. Some of the stories included experiences of family and friends who participants believed were cared for inadequately, that emphasized participants' frustrations with HCPs. Four participants knew what they wanted to say before I arrived for the interviews. One participant waited for me to ask questions. The diversity between participants and their stories was pronounced, demonstrating the individuality of each participant even though they have common experiences of not sharing information with HCPs.

All the participants defined their HCPs as doctors. Three participants also included doctors who were caring for their spouses. Other HCPs were referred to in passing. One participant told me that her doctor demanded that she choose between listening to him or the pharmacist and it was not until the interview that she viewed pharmacists as HCPs. Another participant referred to a radiation technologist as a HCP, but experiences with doctors were her main experience with not sharing information.

At the time of the study, all the participants were seeing their doctors every three months for prescription refills. All participants were choosing not to share information with their doctors during those visits. From the narratives, three themes emerged: Illusions of Care; The Last Straw; and the Mask of the Non-sharing Older Adult.

Themes

Illusions of Care

All participants had expectations about the roles of doctors that were based on their values and beliefs. I found myself feeling shocked and outraged during the telling of their stories, which demonstrated that I had similar expectations. Participants had expectations that doctors would: believe them; have time to provide adequate care; listen in an active engaging manner regardless of the content or the efficiency of the presentation; and offer support on a wide range of life experiences. From the perspectives of the participants, these expectations were rarely realized.

Both Will and Eleanor believed it was beneficial to share information with their doctors. Will said:

> I have always related with my doctors and with my professional healthcare people as openly and honestly as I possibly could realizing that that's the best for them and the best for me I mean they can only help me if I tell them everything and share everything with them.

Eleanor told me that, "…I'd always believed you should tell your doctor everything so they can discover what's wrong with you or help you to avoid being sick…." Will and Eleanor had high opinions in doctors' ability to care for them. Yet, both Will and Eleanor had underlying beliefs that doctors were selective in accepting clients. Will was hospitalized and had no family doctor and was looking for a doctor to be discharged into his or her care when Will told me:

> what doctor would take a sick person already, you know, they like you to be healthy and then if you get sick when you're seeing them, that's one thing but, you know, to actually have a doctor take you when you're sick is not the best thing and I understand that but anyway so that is the situation that I was in.

Eleanor was "…not well…" when she had her first appointment with her doctor. She told me that he said to her "…maybe you'd be more comfortable with somebody else…." But Eleanor knew:

> he was talking about himself that he would be more comfortable without me there and because…he had brought it up not me, it would be different if I had brought it up, right, then it would be me.

So Eleanor "…always had sort of an on/off relationship and I felt a lot of the time that he doesn't totally believe me but that's okay…."

Will and Eleanor believed that sharing information with their doctors was the best way to care for themselves. Will's gratefulness that a doctor accepted him when he was sick suggested that Will had heard stories about doctors not accepting certain clients. Eleanor did not seem shocked that her doctor suggested she find someone else, which indicated that Eleanor was familiar with this practice or treatment.

Maria expected that her doctor would have time for her and would like her doctor to slow down and listen to her, but he was always in a rush and does not have or does not make time for her. Maria said, "…I just felt I was wasting my time because I don't rush to the doctor unless I really need to go." Maria was the only participant who made a comment to her doctor. As she described it, her doctor was yet again rushing out the door during an appointment, when she informed him that it was time for a holiday but she did not think he connected her comment with his behaviour.

Rose had "…total confidence…" in her family of origin doctor who she saw for 31 years, but feels differently with her present doctor saying that "…you're new, he's busy, he hasn't been part of your life, you know, that kind of thing…." She spoke about clients feeling like they should not take up doctors' time when she said, "…I am really concerned with doctors, what appears to me, this is broad, lack of time…but I think we have this perception that we should only take a certain amount of doctors' time…." She expressed nostalgia for the doctor that cared for her family of origin years ago saying, "…yeah, I'd like, I'd like doctors again to be like my first doctor was, he got busy as the years went on but, um, always seemed to be there when I needed him." Rose was aware that her present doctor was not always available.

Isadora expected her and her husband's doctor to make visits to her husband, who was living in a long-term care facility, but the doctor told her he did not do nursing home visits. Isadora expressed anger and told me she had a fight with the doctor after her husband's death. She expected that their doctor would continue to care for her husband even if he lived in a nursing home. She explained to me that she has "…no faith in doctors so I'm very critical of doctors.…"

Maria was the only participant who talked about gender and ageing. She very pointedly told me, "…all the doctors, they don't want to face up to long care of people who have these things" referring to chronic conditions associated with ageing. She further explained, "…doctors don't like women and they don't like nurses, and old women they can't stand, that's geriatrics, they can't stand old people…."

From their unmet expectations of care, participants developed assumptions about relationships with doctors. Isadora and Will experienced that their doctors were no longer helpful to them, so they changed doctors. Years ago Isadora cut herself and went to her doctor asking for a tetanus shot. Her doctor disagreed but Isadora got the shot saying, "…the argument went forward and back and I won…." After being in good health for many years, she returned to him for a newly developed chronic condition, and found that during her weekly visits "…he practically snarled at me, [I] think he hated the sight of me…." The experiences with her doctor left a lasting impression but it was his treatment of her dying spouse that prompted her to change doctors saying, "…that doctor treated [my husband] rotten and I feel it was because of me…." When Isadora made a suggestion about her husband's care to her doctor he told her "…to shut up…and so I did, so I never spoke to him again either, I left there and then I went to another doctor." However, upon reflection, Isadora continued with her first doctor for a while longer before she made a change. Isadora told me "…I couldn't stand that doctor…he held a grudge about that, you could tell it, it was so plain" referring to the tetanus shot.

When Will showed his doctor supplements he was taking, the response from his doctor was "…very negative…" and Will understood that his doctor did not believe in supplements. Will was not familiar with a doctor that disapproved of supplements and did not "…feel that [the doctor] could be a positive influence in my recovery…." Neither Isadora nor Will spoke to their doctors about their feelings.

Rose is a member of a cancer survivors support group that presents information to women in the community. She "…passed on information…" to her doctor about the work this group is doing. She reflected, "…it probably didn't make him very happy…and I don't think he likes me talking about, informing him about…" what this support group is doing. Rose did not say why she thought this but seemed to have an opinion that doctors do not like or appreciate receiving information from clients or from sources other than the doctors themselves.

At a prearranged appointment for her husband in a speciality clinic, Eleanor asked two technologists to get the doctor immediately because her husband was complaining of severe pain. Eleanor was told the doctor was busy, even though they did not attempt to check the doctor's availability. Her continued complaints were ignored until her husband collapsed. Then the doctor arrived but her husband died resulting in Eleanor severing any future relationships with the speciality clinic. She has vowed never to set foot in this clinic again. Another family member is receiving care at the clinic, but she has kept her word and refuses to enter it. Eleanor said, "…I still couldn't understand their reaction to totally ignore me and not help him. I mean what have they got to lose if they listened to me and help him? I couldn't understand it, I still don't…."

Maria did not find doctors in general to be helpful and told of three occasions where she had experiences that particularly upset her. One occasion related to Maria's friend who had what Maria perceived to be some serious medical concerns, possibly dementia, and her friend's doctor said her friend was "…fun, such a pleasant woman, he looked forward to her visit, didn't do a thing, not a thing." Maria was very concerned for her friend but neither Maria nor her friend's husband could get the doctor to believe them about her friend's condition.

On another occasion, Maria had an experience with her dying husband's doctor where she believed she had to appease the doctor. The doctor said to her "…it's all your fault" in reference to something Maria did not fully understand when she said, "I don't know, I don't know what that was so I tried to talk him down on that one…." Instead of the doctor offering support and suggestions to Maria, she believed he verbally attacked her. The last event for Maria was when she discovered that her doctor monitored, by blood test, a specific organ that her chronic disease may compromise, without informing her of the reasons for the test. Maria said, "…well, he might have told me, maybe I should have been watching, maybe there are things I could have done…." Maria found the lack of information from her doctor upsetting.

The participants were struggling to have collaborative relationships with their doctors. Will summed up his opinion of what doctor/client relationships could be when he said, "…the relationship between doctor and patient they should work together…." Isadora laughed when she said that she was "…a little bit, um critical of doctors…I worked with them…." Eleanor said "…I'm not very good with doctors like I used to be a nurse and I, I, I guess really I don't like them very much in the long run of things." Maria said, with some sarcasm in her voice, "he thinks he, he has kept me alive all these years…." Isadora, Eleanor, and Maria had low opinions about doctors but were reliant on the doctors for their prescriptions.

From the participants' perspectives, their doctors were not engaging in their health care. Participants stated they are not believed, not listened to, and their knowledge from life experiences, the Internet, and support groups have been ignored. All the participants experienced their doctors not meeting their expectations. These experiences with doctors led to a moment of decision where the participants had had enough.

The Last Straw

The Encarta World English Dictionary (n. d.) defined a last straw as "a minor annoyance that, because it comes at the end of a series of other misfortunes, turns out to be the thing that makes a situation unbearable." All participants had a last straw event, a significant occurrence that caused a change in their relationship with their doctors. As was suggested in the dictionary definition, the last straw was often minor. The result of the last straw though is significant, and resulted in participants distancing themselves from their doctors by not sharing information. The information not shared was information the participants believed may have compromised or complicated relationships with their doctors. The information may have been beneficial to their health care. However, in the Last Straw, participants gave up their hopes and expectations of collaborative relationships with their doctors. There was a resigned acceptance that their doctors were not going to change.

When Isadora changed doctors, she was hoping to have a better relationship where her new doctor would not hold a grudge. Instead, she found him to be like her first doctor, when he accused her of diagnosing herself and making up a case of angina. Isadora's belief was that her second doctor treated her in this manner because her chart included comments from her first doctor that related to Isadora being "…stubborn and insisted that [she] knew more than the doctor" or something to this effect. She believed that her second doctor read what her first doctor wrote and decided she was "stubborn", so she stopped initiating conversations with her doctor.

Will found he got along well with his second doctor until he showed him the supplements. Will found this doctor's response "…was really negative…", much like the first doctor. So Will researched his supplements on the Internet and took the "…research reports of clinical studies…" to his doctor. His doctor did not read the studies, telling Will that he did not believe the research. Will, with a good understanding of research, continued to take the supplements but did not tell his doctor, which was against his philosophy of working as a team with this doctor.

When Eleanor voiced her grief about her husband's unexpected and difficult death with her doctor, his manner relayed to her to "…smarten up…." He told her "…that was enough now, you continue your life, its all done, oh well, so what…." Eleanor said that her doctor "…seemed almost annoyed…what, what does he have to be annoyed about, I'm the one who's supposed to be annoyed here…." Eleanor recognized that her doctor's judgement, that she should get on with life, did not fit with her need to grieve and talk about the difficult circumstances of her husband's death. These experiences led Eleanor to not wanting to see her doctor again.

Rose relayed some information to her doctor that she received from her pharmacist and he replied, "…you're going to have to decide who you're going to listen to." This comment suggested to Rose that her doctor behaviour was counter-productive to her care, as he did not believe in a team approach to Rose's health. Rose reflected, " …I didn't feel the connection with my doctor as I had…I think there was a change that started when he said that to me about, about the woman, about the pharmacist, I think that started then…." A second event occurred when her doctor forgot her concern of a specific cancer with hereditary factors, which her mother died from. Rose said, "…I just, I couldn't believe that he didn't remember…I was just floored…." Rose went on to explain "…I think I was really at the, the final point where I thought I didn't feel the connection with my doctor as I had…." Rose had an expectation that her doctor would remember information that could be life threatening to Rose.

Maria asked her doctor to send her to a specialist and he refused her request, telling her the prescription he was giving her was the same one a specialist would give her. She was unhappy with his decision and told me that she "…won't ask him to send me again."

There was a change in participants' attitudes, when they decided to relate differently with their doctors by not sharing information with them. The participants were aware they could not change how their doctors behaved, but they could change the information they gave to their doctors, thereby controlling their doctors' responses.

The Mask of the Non-sharing Older Adult

Participants explained how they interacted with their doctors after they choose not to share information. Will said his doctor "closed me down…and I didn't want to share anything with him, I just wanted to get away from him" which resulted in Will not sharing that he continued to take supplements and was also seeing a naturopath saying:

> I just feel because of the experience I've had already that it wouldn't benefit it would just muddy the waters, it would just make waves and that's the last thing I need at this point…I can't tell him about the other stuff because he wouldn't understand anyway and if he doesn't understand he's going to be negative.

Isadora said:

> I go for my pills, I take blood pressure pills and I just go, he tells me to come once every three months, so I go once every three months, he checks my blood pressure and gives me a prescription for my pills, I get them filled and that's it, that's what I've been doing for the last two to three years…he looked at my file

> and he said oh we haven't done a blood test or anything for at least a year and I, I don't say anything so he ordered some blood tests so I go and get some blood tests.

Eleanor said:

> I don't want to see him really…I don't want to see him and I won't go unless I, well I have to go every three months to get my drugs redone but other than that I don't and he keeps telling me I have to come for a, an annual exam and all these other things I'm not going, I haven't gone, I don't know when or if I ever will to be honest.

Rose believed that she *should* share some specific information with her doctor but choose not to because "well the consequence will be the same attitude probably that I've had from him before…he'll be critical…." She acknowledged that she diverts the conversation by excessive talking "oh yeah and then when I'm in there I've got all other things to talk about but not that" so that her doctor did not have an opportunity to ask her questions. Rose says, "…I can't lie to him, I can't lie…" to her doctor, but she does not offer the information.

Maria shared with her doctor only if he asked questions, but she found her doctor does not ask her any questions "…because he's moving to the door to go out." Maria felt she is wasting her time going to her doctor because he is too busy to ask questions. Maria's belief is that "…he should ask me those things…" referred to her belief that her doctor should ask why she was there. Maria's comments indicated her desire to not interact with her doctor.

Will, Isadora, Eleanor, and Maria answered their doctors' questions but did not initiate conversations while Rose diverted the conversation with excessive talking. The intention of not sharing information was present with all participants. For these participants, not sharing information was intentional and pre-planned. The participants had a desire to share with their doctors, but they were treated as if they knew nothing about their bodies. Will said "…so once again I got, kind of put up a shield and a defensive thing…" when he sees his doctor.

Rose and Will used the media and Internet to gain knowledge about their health conditions and concerns. They demonstrated a thirst for knowledge to be partners in their own care. Maria's expectations were that her doctor was her source of medical information; that he should know the questions to ask and the solutions to her health concerns.

At the time of the interviews all participants had no plans to change the way they related to their doctors - they will continue not to share information. With their ages and chronic diseases the chances of needing more than their current prescription refills every three months is certainly a reality. Isadora, Eleanor, and Will have thought about the future when they may require more care. Isadora stoically told me, she was "…tough, I'll survive and I'll live till I die." However, later in our conversation she reflected that she does worry about the future saying

> I get something wrong and I'm bound to…and I don't know who else to go to…." and "…I don't know what I would do if I got sick because I can't talk to my doctor…so I'm stuck and there aren't any other healthcare people that I know of.

Maria also made a stoic comment saying, "…because I can usually get through those things, I've got a thick skull." She did not refer to plans for her future. Eleanor was unsure about having her overdue annual physical saying,

> I don't think it will matter for this time, um, not really, I mean, no, I don't think it will matter, and in the future I might go and get the, you know, what he wants me to do I might, I don't know now.

Will was fearful that if he discussed the supplements again that his doctor "…might take a more aggressive negative stance, um like I said to the point of just, you know, firing me as a patient." Isadora told me "…I can't argue with the doctor" which demonstrated an understanding that the doctor is in charge. Will's and Isadora's experiences have led them to believe that their doctors are in charge and have power over them, leaving them in vulnerable positions. The "power-over" relationship was also evident when Eleanor was ill and her doctor suggested she look for another doctor.

Increased need of a doctor is a factor of ageing. Isadora had given some thought to her future health care whereas Maria said she was not nervous about her health because she has always looked after herself, yet Maria is having difficulty in getting her doctor to refer her to a specialist. Will has pretended to follow his doctor's advice about not taking supplements while continuing to take them. Eleanor was unsure what she would do for her future health care. At the time of the interview, she was not concerned, but she appeared weary when she talked about making future decisions regarding health care. Rose told me "…I just thought, em, take care of yourself…."

The participants experienced anxiety from not sharing information with doctors. Being selective in what they said during doctor appointments, also led to some participants finding themselves in conflict with their philosophy and beliefs that sharing and interacting with doctors was important to their health care. If the doctors have any awareness about the participants not sharing information, it was not apparent to the participants.

Summary

The flow of the themes: Illusions of Care; The Last Straw: and The Mask of the Non-sharing Older Adult were similar in each of the participants' stories. Participants expected their doctors to believe them, have time for them, listen in an active responsive manner, and be open to suggestions and discussions. However, participants experienced their doctors as being too busy for them, selective in accepting clients, and emotionally unavailable. Commonality and diversity among participants was present, adding authenticity to the findings. Regardless of the similarities and differences between participants' stories, the findings showed that the participants are at risk when they choose not to share information with their doctors.

Chapter 5 – Discussion

The purpose of my research is to explore the experiences of older adults who choose not to share information with HCPs. I use the narrative inquiry methodology of Riessman (2008) to listen to the stories of five older adults. I identified three narrative themes using interpretive analysis of the participants' experiences: *Illusions of Care*, that describes the participants' experiences with doctors before they choose not to share information; *The Last Straw*, the incident that caused participants to choose not to share information; and *The Mask of the Non-sharing Older Adult,* to explain how participants interacted with their doctors after they choose not to share information.

Significance of the Study

Older Adult and Doctor Relationships

This study presents a view of the relationships between doctors and older adults who chose not to share information with them. The participants in this study described continuously struggling to develop a shared responsibility for their health, only to feel ignored, not believed, and threatened. Older adults require collaborative relationships where doctors are in partnership with them (Donovan & Blake, 1992; Playle & Keeley, 2001), to make informed choices about their health and health care so that they are more likely to share information and thereby decrease the risks they are taking (Lovell, 2008).

Participants in my study describe their doctors' behaviours as the reason for not sharing of information. Two participants changed doctors, only to find that their new doctors behaved in similar manners. Participants describe their doctors as controlling information, both given to and received from, the participants. The behaviours of the doctors eventually result in the decision of the participants not to share information.

Some medical schools teach respectful behaviours with an emphasis on developing positive client relationships (Gordon, 2003; Parker et al., 2008). It is unknown if the doctors referred to in my study received such courses in professional development as part of their curricula. I find it surprising, and in fact shocking, that participants experienced their doctors' behaviours so negatively, particularly with some medical schools addressing positive relationships with clients. However, if the doctors referred to in my study graduated from the "old school" where doctors were considered the gatekeepers of information, it may be not so surprising. It is important to note that this study did not include the doctors' perspectives of the participants.

Today older adults bring knowledge from many sources and may be more current in some aspects of treatment of their diseases than their doctors (Lovell, 2008). In my study, one doctor told a participant that he did not believe in alternative supplements even when the participant showed him the information he had researched on the Internet. This example demonstrates that today, older adults have more access to knowledge, through the Internet, support groups, and knowledgeable family and friends.

Alternative supplements and therapies are becoming more common, with the number of visits to alternative practitioners outnumbering visits to doctors in the United States (Barrett et al., 2000). It is common that clients who visit alternative practitioners do not tell their doctors (Barrett et al., Lovell, 2008). These finding are consistent with my finding, where one participant who visits an alternative health care practitioner, chooses not to tell his doctor because of the previous comments about alternative supplements his doctor has made. Client visits with alternative health care practitioners, or even other doctors, are seldom addressed in the literature.

Hareli, Karnieli-Miller, Hermoni, and Eidelman (2007) state there have been no studies before 2007 that considered doctors' feelings when clients found other doctors. The authors state that some doctors experienced hurt feelings when clients left them, especially if the relationship was lengthy and the clients had significant social and financial status. As older adults are often considered less valued in Western society, it may be that older adults' leaving a doctor's care has little impact on their doctors.

It is unknown if the doctors referred to in my study behave in the same manner with their other clients who fit into different age, socioeconomic, and educational groups. Did the doctors referred to in my study treat their other clients differently than my participants, and if so is it because of the participants' age, financial, or educational status? What is clear is that there is a range of questions still unexplored that would be beneficial for future studies.

Whatever the origins of the encounters the participants have with their doctors, the participants face the very real dilemma of how to continue receiving care from their doctors. Choosing not to share information is a way for participants to continue with their doctor visits yet keeps some distance from what they perceive as barriers to sharing information.

Ageing as a Non-issue

None of the participants expressed concern about ageing, losing their independence, or being placed in a facility, which is often identified in the literature as a factor for not sharing information (Dugan & Bonds, 2003; Featherstone & Hepworth, 1991). The participants did not suggest that the behaviours of their doctors were related to being older. Only one participant in my study stated that a doctor did not like or want to care for older adults. The participants did not refer to themselves as being old, so did not view the comments and behaviours of their doctors as related to their age. This self-view is common, as older adults often do not see themselves as old (Cremin, 1992). More first person research is needed to truly understand if older adults view their ageing as a factor for some of the less than desirable behaviours of their doctors.

Sensitive Topics

After I read the literature, I had wondered if sensitive topics might present as factors for not sharing information, but only one participant discussed alcoholism as a sensitive topic for her not sharing information. The other four participants did not discuss sensitive specific sensitive topics as the reason for not sharing information. The sensitive topic for the all the participants was sharing that they did not share!

Sharing They Did Not Share

Advertisement in the local newspaper, placement of posters, rewording and reposting posters, being profiled in the local newspaper, and speaking to a seniors group about the study generated only five participants. The two communities in which the participants lived have a higher than average population of older adults in Canada with median ages of 55.0 and 60.0 (Statistics Canada, 2006). The small number of participants was a surprise to me considering the large population of seniors in the area.

Some older adults may not have responded to the advertisements because they could not read, did not get out to public places to view the posters, or were too ill to participate. Some older adults may not have participated because the small geographical area created a fear of exposure. Perhaps only the older adults with the worst experiences became participants of my study, as it is often only the worst experiences that people discuss. Were the five participants, plus one who was unable to participate because of illness, the only older adults in the area who did not share information with HCPs? Did some older adults not participate because they believed they did share information with HCPs? One participant said she shares information with her doctor, despite volunteering for the study, but contradicted herself during the interview when she told me about her experiences that led to her not sharing information with her doctor. Overall, the topic of sharing that they do not share is sensitive in nature to the participants.

Older Adults in the Health Care System

The structure of the British Columbia health care system promotes cure rather than care, which tends to promote power-over relationships between HCPs and their patients. It is no wonder that the older adults in my study had issues with perceiving their doctors behaviours as being counter-productive to sharing information. Some of the participants' experience they are rushed during office visits and attribute this rushing to the doctor being uninterested in their concerns. The commonly experienced seven-minute appointment time to discuss only one condition is certainly not conducive to developing positive older adult/doctor relationships.

It must be acknowledged though that doctors are also working within a system that constricts their time and the number of clients they are permitted to see in a day. Doctors are often rushing to stay on time because the next client is waiting. I complain if I have to wait for my appointment when my doctor runs late. I believe my doctor is wasting *my* time by keeping me waiting. Time is now a commodity in the doctor-patient relationship. The health care system has created barriers to the older adult-doctor relationship, which may negatively influence the quality of care (Lovell, 2008). Shared responsibility for one's health is challenging as the health care system is designed with doctors to be the primary decision-makers. The pyramid of professional power is also evident as other HCPs, such as nurses, take "orders" from the doctors. The issue of how the medical model health care system creates barriers for both older adults and doctors could be addressed in future research.

Limitations of the Study

Participants' Definition of the Term "Health Care Professionals"

The participants in this study self-defined the term 'health care professionals' as being medical doctors. Two participants referred to other professionals as HCPs, but these were only mentioned incidentally. It was not until the interview that a third participant realized that pharmacists are also classified as HCPs.

Further research is needed to understand what the term 'health care professional' may mean to older adults. I used the term 'health care professional' to encompass any health professional, in the hopes that participants would be free to discuss not sharing with those other than doctors. I did not use the term 'heath care providers' because providers can be those who are not professionals, such as nurse aides. The medical dictionary defines the term ‘health care’ as all services available by medical professionals (Venes, 2001) yet ‘allied health professional’ is a term described as those who are specially trained, such as physiotherapists, (Venes) but not doctors and nurses. Older adults cannot be expected to understand the term ‘health care professional’ if HCPs themselves cannot agree on a definition. Upon reflection, I would consider using a different term if I was to continue with the research. However, more research is needed to determine if doctors are the only HCPs the participants did not share information with or if doctors are the only professionals that the participants identified as HCPs.

Multiple Stories

It is unknown if the participants in this study are referring to only two doctors in the community but it is more likely that the doctors referred to are more than two. It is even possible that seven different doctors are being referred to, as there are approximately 30 General Practitioners in the community.

As I reflect on the finding of this study, I am surprised by the participants’ perceptions of doctors. Three of the participants, two retired nurses and a retired social worker, worked with doctors in a professional capacity before they retired. They admitted to being critical of doctors from their work experiences with doctors, yet it could be argued that they have more highly developed skills in communicating their issues to physicians. The work experiences of these three participants are embedded in their present day experiences influencing their feelings about the care their own doctors provide.

This study does not include the stories of the doctors that the participants refer to. Not hearing the stories of the doctors creates a limitation in understanding the relationships between the participants and the doctors. Future research could include not only the perceptions of doctors, but also alternative practitioners and family members to provide a more complete picture to this complex issue.

My Understanding

Returning to the beginning, I understand the factors that may have influenced the decision of the older woman in the ophthalmologist's office who did not share that she could not see after her procedure. I now have a better understanding of the complexity of the phenomenon of older adults who choose not to share information with their doctors. From the literature search and my own experience, I was aware before I interviewed participants that older adults placed themselves at risk when they did not share information. I thought not sharing information would present as a one-time event or as the literature discusses, related to specific issues, such as falls. I was unaware that not sharing of information could be a continuous way of being. I now understand that the participants are at risk from worsening chronic conditions or undiagnosed new conditions or diseases, if they do not share information on an ongoing basis.

There is discussion in British Columbia that in the near future some clients can receive certain prescription refills from their pharmacists, without seeing their doctors. I wonder how this possible change in the health care system will affect the participants in my study. From the intensity of the feelings of the participants, I perceive they will not return to their doctors if they do not have to which may lead to not returning to their doctors should new conditions develop.

The phenomenon of older adults not sharing information is much larger than what this study discusses. Future research could include many more factors, such as understanding the doctors, how participants present themselves during visits, and if participants would share information if their health changes.

Contributions of This Study for All Health Care Professionals

Historically, all HCPs, not just doctors, are engaged as the gatekeepers of information, sharing with clients what they think clients should know. To encourage interdisciplinary care, Health Canada funded the initiative, Enhancing Interdisciplinary Collaboration in Primary Health Care (ECIP) (n. d.), for primary health care. EICP acknowledges the need for research that is relevant to all primary health care disciplines. Following the EICP initiative, all HCPs can profit from reading my study, which will improve communication between HCPs and older adults.

This study tells HCPs that they need to interact with older adults in a manner that creates a safe place to share. HCPs need to be aware that older adults are interested in their own care, need time to ask questions, do not view themselves as old, and are knowledgeable about their conditions.

First person narratives are an effective tool to understand the stories of older adults who choose not to share information with HCPs as it facilitates learning about the experiences of the participants rather than just learning about them from researchers' points of view. First person accounts are significant to all HCPs, even though in this study doctors are the professionals that participants chose not to share information with. When HCPs have a collaborative relationship with clients, clients feel safe to share information and HCPs are more likely to perceive subtle changes in the clients' condition when there is a trusting relationship (Rini, 2004).

Narrative inquiry provides an effective method to study the complex phenomenon of older adults who chose not to share information with HCPs both the personal and social factors of older adults not sharing information is illuminated. Appreciating the complexity of the phenomenon provides HCPs with a better understanding of older adults.

Implications for Care

Chronic health conditions require a correct diagnosis. Early diagnosis provides older adults with opportunities to learn about their conditions and how to live with them. All the participants have at least one chronic condition that requires a visit to their doctor every three months for prescription refills. This choice to not share information appears not to have had a notably negative impact so far, but the question remains "What will happen when their condition worsens or they develop another condition or disease."

The future health of the participants in this study is of great concern. One participant had chosen not to have a physical examination, which is overdue. Another participant has self-diagnosed and treated herself with prescription medication remaining from a previous treatment. Some participants did express concern for their future health care. Each participant believed that they must care for themselves and not rely on their doctors. The participants will determine for themselves when to seek additional medical attention. The risks participants are placing themselves in were not fully described in this study and therefore remain unknown. More research is needed to understand the health risks older adults take when they do not share information with doctors.

Implications for Future Research

Older adults in this study made the decision not to share information after enduring behaviours from their doctors that they perceived as counter-productive to sharing information. More research is needed to explore if doctors treat older adults differently from their other clients. Research focusing on doctors' behaviours and attitudes regarding older adults are absent from the literature. Gaining the doctors' perspective may broaden the overall understanding of the relationship between doctors and older adults.

Future research should include HCPs other than doctors. It is important for all HCPs to gain a better understanding of older adults who choose not to share information. Future research should take into consideration any differences between communication between doctors and older adults and between older adults and other HCPs. It is also important to understand how HCPs can assist older adults in sharing information. Research that includes both older adults who do not share information and the HCPs themselves will further enhance understanding the phenomenon.

With participants placing themselves at risk by not sharing information, it is important to understand how conditions and diseases may worsen or develop. Future research should include ways of discussing the risks that older adults place themselves in when they do not share information with HCPs. It is imperative though that older adult' choices are respected as this study shows that older adults make choices about not sharing information based on their relationships with HCPs regardless of the risk to their health.

Summary

Older adults' choosing not to share information with HCPs is a multi-faceted phenomenon that is not easily explained or understood. This study does not solve the concern of older adults not sharing information with HCPs but it does present a glimpse into the older adults' experiences. Understanding the experiences of older adults will inform and guide the practice of HCPs, leading to better communication between themselves and older adults, resulting in older adults sharing information.

Bibliography

Banister, E. M. (1999). Evolving reflexivity: Negotiating meaning of women's midlife experience. *Qualitative Inquiry, 5*(1), 3-23.

Barrett, B., Marchand, L., Scheder, J., Appelbaum, D., Chapman, M., Jacobs, C. et al. (2000). Bridging the gap between conventional and alternative medicine. *The Journal of Family Practice, 49*(3), 234-239.

Black, J. (2007). Palliative care of older people. Working with older people: Community care policy and practice. *National Council for Palliative Care, 11*(3), 21-23.

Bok, S. (1989). *Secrets: On the ethics of concealment and revelation*. New York: Vintage Books.

Bok, S. (1999). *Lying: Moral choice in public and private life*. New York: Vintage Books.

British Columbia Institute of Technology. (n. d.) Retrieved May 20, 2008 from http://www.bcit.ca/path/health/programs/

British Columbia Medical Association, News/Publications, Wait List Report II. (n. d.). Retrieved April 17, 2008 from http://www.bcma.org/public/news_publications/publications/waitlistreport/executivesummary.asp

British Columbia Ministry of Attorney General. (n. d.). Retrieved September 21, 2008 from http://www.ag.gov.bc.ca/mandatory-retirement/

Brown, L. (Ed.). (1993). *The new shorter oxford English dictionary.* New York: Oxford University Press, Inc.

CNA (2002). *Ethical Research Guidelines for Registered Nurses.* Ottawa, ON: Author.

Coupland, N., Coupland, J., Giles, H., Henwood, K., & Wiemann, J. (1988). Elderly self-disclosure: Interactional and intergroup issues. *Language & Communication, 8*(2), 109-133.

Cremin, M. C. (1992). Feeling old versus being old: Views of troubled aging. *Social Science & Medicine, 34*(12), 1305-1315.

Donovan, J. L., & Blake, D. R. (1992). Patient non-compliance: Deviance or reasoned decision-making? *Social Science & Medicine, 34*(5), 507-513.

Dugan, E., & Bonds, D. (2003). Explaining the lack of communication about falls and the fear of falling. *Generations: Journal of the American Society on Aging, 26*(4), 48-52.

Dugan, E., Roberts, C. P., Cohen, S. J., Preisser, J. S., Davis, C. C., Bland, D. R., et al. (2001). Why older community-dwelling adults do not discuss urinary incontinence with their primary care physicians. *Journal of the American Geriatric Society, 49*(4), 462-465.

Ebersole, P. (2004). Geriatric nursing and an aging society. In P. Ebsersole, P. Hess, & A. S. Luggen (Eds.), *Toward healthy aging: Human needs and nursing response* (6th ed.) (pp. 1-26). St. Louis, MO: Mosby.

Encarta World English Dictionary (n. d.). Retrieved June 10, 2008 from http://encarta.msn.com/dictionary_/last%2520straw.html

Enhancing Interdisciplinary Collaboration in Primary Health Care (EICP). (n. d.). Retrieved August 10, 2008 from http://www.eicp.ca/en/default.asp

Featherstone, M., & Hepworth, M. (1991). The mask of ageing and the postmodern life course. In M. Featherstone, M. Hepworth, & B. S. Turner (Eds.), *The body: Social process and cultural theory* (pp. 371-389). Thousand Oaks, CA: Sage Publications.

Feldman, S. (1999). Please don’t call me ‘dear’: Older women’s narratives of health care. *Nursing Inquiry, 6*(4), 269-276.

Frid. I., Öhlén, J. & Bergbom, I. (2000). On the use of narratives in nursing research. *Journal of Advanced Nursing, 32*(3), 695-703.

Fulks, J. S. & Molinari, V. (1995). The youngest-old and the old-old: Issues of well-being, the family, and social support. *Journal of Geriatric Psychiatry, 28*(2), 197-217.

Gordon, J. (2003). Fostering students’ personal and professional development in medicine: A new framework for PPD. *Medical Education 37*, 341-349.

Government of British Columbia, Ministry of Health, Medical Services Plan of British Columbia, Medical and Health Care Benefits. (n. d.). Retrieved April 27, 2008 from http://www.health.gov.bc.ca/msp/infoben/benefits.html

Government of British Columbia, Ministry of Health, Medical Services Plan of British Columbia, Legislation and Governance of the Medical Services Plan. (n. d.). Retrieved December 5, 2007 from frequently asked questions http://www.health.gov.bc.ca/msp/legislation/

Greene, M. G., Adelman, R. D., Rizzo, C., & Friedmann, E. (1994). The patient's presentation of self in an initial medical encounter. In M. L. Hummert, J. M. Wiemann, & J. F. Nussbaum (Eds.), *Interpersonal communication in older adulthood: Interdisciplinary theory and research* (pp. 226-252). Thousand Oaks, CA: Sage Publications.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry, 10*(2), 261-280.

Hareli, S., Karnieli-Miller, O., Hermoni, D., & Eidelman, S. (2007). Factors in the doctor-patient relationship that accentuate physicians' hurt feelings when patients terminate the relationship with them. *Patient Education and Counseling 67*, 169-175.

Health Canada. (2002). *Canada's Aging Population.* Ottawa: Public Works and Government Services Canada.

Hess, P. (2004). Theories of aging. In P. Ebsersole, P. Hess, & A. S. Luggen (Eds.), *Toward healthy aging: Human needs and nursing response* (6th ed.) (pp. 27-55). St. Louis, MO: Mosby.

Hess, P., & Ebersole, P. (2004). Health and wellness. In P. Ebsersole, P. Hess, & A. S. Luggen (Eds.), *Toward healthy aging: Human needs and nursing response* (6th ed.) (pp. 56-78). St. Louis, MO: Mosby.

Hill, C., & Luggen, A. S. (2004). Common Chronic Problems. In P. Ebsersole, P. Hess, & A. S. Luggen (Eds.), *Toward healthy aging: Human needs and nursing response* (6th ed.) (pp. 205-278). St. Louis, MO: Mosby.

Holloway, I., & Wheeler, S. (1995). Ethical issues in qualitative nursing research. *Nursing Ethics 2*(3), 223-232.

Johnson, M. N. (1979). Anxiety/stress and the effects on disclosure between nurses and patients. *Advances in Nursing Science, Jul; 1*(4), 1-20.

Jourard, S. M. (1971). *The transparent self* (revised edition). New York: D. Van Nostrand Company.

Lau, H. S., Beuning, K.S., Postma-Lim, E., Klein-Beernink, L., de Boer, A., & Porsius, A. J. (1996). Non-compliance in elderly people: Evaluation of risk factors by longitudinal data analysis. *Pharmacy World & Science, 18*(2), 63-68.

Li, X., Guh, D., Lacaille, D., Esdaile, J., & Anis, A. H. (2007). The impact of cost sharing of prescription drug expenditures on health care utilization by the elderly: Own-and cross-price elasticities. Health Policy, 340-347.

Lovell, B. (2008). *How communications between physician and patient affect concordance, compliance, and patient safety in a Canadian setting.* Paper presented at the Health Care Systems, Ergonomics, Patient Safety conference, Strasbourg, France, June, 2008.

Luggen, A. S. & Hill, C. (2004). Mobility. In P. Ebsersole, P. Hess, & A. S. Luggen (Eds.), *Toward healthy aging: Human needs and nursing response* (6th ed.) (pp. 378-416). St. Louis, MO: Mosby.

MacDonald, Ann-Marie. (2003). *The way the crow flies.* Toronto, CA: Alfred A. Knoff Canada.

Malhotra, S., Karan, R. S., Pandhi, P., Jain, S. (2001). Drug related medical emergencies in the elderly: role of adverse drug reactions and non-compliance. *Postgraduate Medical Journal, 77*, 703-707.

Ministry of Health Services. (2004). *A profile of seniors in British Columbia.* British Columbia: Author.

Mitnitski, A. B., Graham, J. E., Mogilner, A. J., & Rockwood, K. (2002). Frailty, fitness and late-life mortality in relation to chronological and biological age. *BMC Geriatrics, 2*(1). Retrieved October 26, 2007 from http://www.biomedcentral.com

Moore, P. (1985). *Disguised!* Waco, TX: Word Books.

Morris, W. (1975). *The heritage illustrated dictionary of the English language: International edition*. New York: American Heritage Publishing Co., Inc.

O'Hanlon, A. & Coleman, P. (2004). Attitudes towards aging: Adaptation, development and growth into later years. In J. Nussbaum & J. Coupland (Eds.), *Handbook of communication and aging research* (2nd ed.) (pp. 31-63). Mahwah, NJ: Lawrence Erlbaum Associates.

Ohio State University Extension, The Ohio department of Aging (n. d.). *Senior series: When does someone attain old age?* Retrieved November 25, 2004 from http://ohioline.osu.edu/ss-fact0101.html

Parker, M., Luke, H., Zhang, J., Wilkinson, D., Peterson, R., & Ozolins, L. (2008). The "Pyramid of professionalism": Seven years of experience with an integrated program of teaching, developing, and assessing professionalism among medical students. *Academic Medicine: Journal of the Association of American Medical Colleges 83*(8), 733-741.

Playle, J. F., & Keeley, P. (1998). Non-compliance and professional power. *Journal of Advanced Nursing, 27*(2), 304-311.

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and Methods* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.

Riessman C. K. (2008). *Narrative Methods for the human sciences.* Thousand Oaks, CA: Sage Publications, Inc.

Rini, A. G. (2004). Economic, health care, and legal issues. In P. Ebsersole, P. Hess, & A. S. Luggen (Eds.), *Toward healthy aging: Human needs and nursing response* (6th ed.) (pp. 431-449). St. Louis, MO: Mosby.

Rowe, J., W., & Kahn, R. L. (1987). Human aging: Usual and successful. *Science, 237,* 143-149.

Rowe, J., W., & Kahn, R. L. (1997). Successful ageing. *The Gerontologist, 37*(4). 433-440.

Russell, C. (2007). What do older women and men want: Gender differences in the 'lived experience' of ageing. *Current Sociology, 55*(2), 173-192.

Saarni, C., & Lewis, M. (1993). Deceit and illusion in human affairs. In M. Lewis & C. Saarni (Eds.), *Lying and deception in everyday life* (pp. 1-20). New York: The Guilford Press.

Scott, Walter. (1808). Marmion, Canto vi. Stanza 17. Retrieved February 25, 2007 from http://www.quotationspage.com/quotes/Sir_Walter_Scott/

Statistics Canada. (2006). Retrieved August 23, 2008 from http://www12.statcan.ca/english/census06/data/

Stephens, J. (1976). *Loners, losers, and lovers: Elderly tenants in a slum hotel.* Seattle, WA: The University of Washington Press.

U. S. Social Security Administration. (n. d.). Retrieved August 1, 2006 from http://www.ssa.gov/pubs/10043.html#part3

van Manen, M. (1997). *Researching lived experiences: Human science of an action sensitive pedagogy* (2nd ed.). London, ON: Althouse Press.

Venes, D. (Ed.). (2001). *Taber's cyclodepic medical dictionary* (20 ed.). Philadelphia: F. A. Davis Company.

Wilkes, L., Cert, R., & Beale, B. (2005). Role conflict: Appropriateness of a nurse researcher's actions in the clinical field. *Nurse Researcher, 12*(4), 57-70.

Wroe, A. L. (2002). Intentional and unintentional nonadherence: A study of decision making decisions. *Journal of Behavioral Medicine, 25*(4), 355-372.

Zauszniewski, J. (1996). Self-help and help-seeking behavior patterns in healthy elders. *Journal of Holistic Nursing, 14*(3), 223-236.

Appendix

Appendix A – Advertisement

VOLUNTEERS NEEDED

FOR A NURSING STUDY

- **Are you 65 years or older?**
- **Are you aware of choosing not to share some information with a health care professional in the past five years?**

If you answered yes to the above questions I would like to hear about your experience. The interview will take approximately 60-90 minutes of your time with a possible follow up interview.

The research is confidential, unpaid, and voluntary.

I am a Registered Nurse in the master's program at the University of Victoria but living in Qualicum Beach.

For more information please call
Shelagh Brennan, RN, BSN
250-951-7077

This study has been reviewed by and received ethic clearance through the University of Victoria Research Ethics Board.

Appendix A.1 - Advertisement

DO YOU TELL YOUR HEALTH CARE PROFESSIONAL EVERYTHING?

Are you 65 years of age or older?

Are you aware of choosing not to share information with your doctor or other health care professionals in the past five years?

If these questions raised your interest, I would like to talk with you. I am a Registered Nurse enrolled in the Masters Program at the University of Victoria, but living in Qualicum Beach.

The purpose of this study is:

- To gain an understanding of the experiences of older adults who choose to share/not share information with health care professionals

You will be asked to:

- participate in one “in person” interview
- the interview will take approximately 60 to 90 minutes of your time with a possible follow up discussion
- the interview will be arranged at a convenient time and place

The research is confidential, unpaid, and voluntary
For more information please call Shelagh Brennan RN, BSN

250-951-7077

This study has been reviewed by and received ethic clearance through the University of Victoria Research Ethics Board

Appendix B – Questions

Opening:

When we talked on the telephone you told me that you were aware of a time when you choose to not share some information with a health care professional. I am asking about your experience. There are no right or wrong answers…only your story.

Questions:

Tell me about a time when you chose to not share some information with a health care professional.

Probe:

Health care professionals include nurses, doctors, physical therapists, occupational therapists, and dentists to name a few.

How did you come to not share this information with your (title of the health care professional)?

Probes:

What was it like for you when you were with the (title of the health care professional) at that time?
What were your reasons for choosing to not share information?
When you shared information how did your reasons differ from choosing to not share information?
Was your reason for not sharing pre-planned or an 'in-the-moment' decision?
What happened as a result of not sharing the information?

How do you feel about your decision to not share some information?

Probes:

How has choosing to not share some information influenced your relationship with (title of health care professional)?
What do you believe the response might have been from your (title of health care professional) if you had shared the information?
What were you hoping might happen by choosing to not share information?

What would have made it okay for you to share the information with (title of health care professional)?

Probe:

Can you tell me more about that?

Appendix C - Participant Consent Form

You are invited you take part in a study where you tell me about a time in your life when you chose to share or not share some information with a health care professional in the past five years.

This study will gather information about your experience.

This study is important because older adults are often misunderstood when they choose to share or not share information with a health care professional. Your story will assist me in understanding your reasons.

You have been invited to participate in this study because you answered the advertisement, you are 65 years or older, and you wish to tell me about a time when you chose to not share some information with a health care professional.

Shelagh Brennan RN BSN sic conducting research as part of her requirements of her master's degree in nursing. I can be contacted by telephone at 250-951-7077 or by email at shelbren@telus.net.

The research is being conducted under the supervision of Dr. Laurene Sheilds of the University of Victoria, who can be contacted by telephone at 25-721-8050 or by email at lsheilds@vic.ca.

You choose whether or not you would like to take part in this study.
Your participation is voluntary and would be appreciated.

If I choose to take part in this study what will I do?
If you take part in this study, you will be invited to:

- Attend an interview with me that will help me to understand your decision to share or not share some information with a health care professional.
- Rest and bathroom breaks will be offered and you can request a break at any time.
- A follow-up interview may be required to discuss my understanding of your experiences.

How long and where will this take?

The first interview will take about 90 minutes of your time. The follow-up interview will take about 30 minutes of your time.

The interviews will take place at a mutually agreed upon location.

What are the risks associated with taking part in this study?

If you take part in this study there is some chance that you might become upset or embarrassed by revealing the time when you did or did not share some information with a health care professional.

To prevent or deal with this risk the following steps will be taken:

- I will tell you the questions I am going to ask ahead of time.
- If at any time during the interview you become upset, I will offer to call the support person of your choosing.
- I will ask for the name and telephone number of your support person before the interview begins.

What are the benefits associated with taking part in this study?

You may benefit from the study by gaining insight into what influence your decision to share or not share some information with a health care professional.

Will participation in this study be confidential?

No personal information will be used other than the information you tell me. Aliases will be used. The study will be presented so that no one can identify you from the writing.

As a registered nurse, I am obligated to report any abuse to or by you. If any abuse is reported to me, I am required to report the information to the appropriate authority. Report of abuse is the only time I would break your confidentiality.

Will I receive any payment for taking part in the study?

No, you will not receive any payment for taking part in the study.

During the Study:

- You be asked questions about the time you chose to share or not share some information with a health care professional.
- The interview will be audio taped, using two audio tape recorders (two are used in case one breaks).

- You may end the interview at any time.
- You may change your mind and withdraw from this study at any time. There is no need to explain why you have changed your mind.
- If you change your mind, you will be asked permission to use your contribution in the analysis and final report of this study. You may agree or refuse this request without explanation.

After the study:

- Findings from this study will be reported in my thesis and may be reported in journal articles, books, the Internet, and other media. It may also be presented in scholarly meetings, workshops, and conferences.
- Your name will not be used in these publications or presentations.
- Information collected during this study will be stored in a locked filing cabinet in my home and on my password protected computer.
- Consent forms and aliases will be stored in a separate locked filing cabinet in my home.
- Information collected during this study will be stored until my thesis is complete, approximately August 2008.
- Except for the transcribed data, all information will be disposed of by shredding paper, erasing cassette tapes, and deleting and emptying the trash of electronic files.
- Research data may be analyzed, now or in the future, by myself or other persons for purposes other than this research project.
- Transcribed data will be kept for purposes of secondary analysis for a period of five years at which time the papers will be shredded.

If you have any questions or if you would like to discuss this study further please contact me, Shelagh Brennan,
250-951-7077 or shelbren@telus.net

Please remember that your participation in this study is voluntary
Thank you for considering this request

Consent:

I have read this consent letter…………………………………..yes…….no

I have had the opportunity to ask questions ………..………..yes…….no

I understand that my participation in this study is voluntary ......yes……no

I understand that I can withdraw my consent at any time……...yes…….no

I agree to take part in the study……..………………………yes……no

I agree to have my interviews taped…………………………yes…….no

Name of Participant: ……………………………………………………..

Signature: ………………………………………………………………..

Date: ……………………………………………………………………

Name of support person……………………………………………………

Phone number of support person……………………………………………..

A copy of this consent letter will be left with you and the researcher will take a copy.

The Human Research Ethics Board at the University of Victoria has approved the ethical conduct of this research.

If you have any questions about the ethical conduct of this research, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca

Appendix D - Consent to Use Data After Participant Withdrawal

You have participated in this study and have decided to withdraw.

If you agree, I would like to keep the information you have given me so far to include in my study.

The use of your information will be voluntary. You will not receive any payment for me using your information.

Shelagh Brennan RN BSN sic conducting research as part of her requirements of her master's degree in nursing. I can be contacted by telephone at 250-951-7077 or by email at shelbren@telus.net.

The research is being conducted under the supervision of Dr. Laurene Sheilds of the University of Victoria, who can be contacted by telephone at 25-721-8050 or by email at lsheilds@vic.ca.

Your signature below indicates that you understand the above conditions of using your information in this study and that you have had the opportunity to have your questions answered by me.

____

Name *Signature* *Date*

A copy of this consent will be left with you and a copy will be taken by the researcher.

The Human Research Ethics Board at the University of Victoria has approved the ethical conduct of this research.

If you have any questions about the ethical conduct of this research, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca