Perspectives on the Use of Medication in Aging Populations

by

Lesya Zubach

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

In partial fulfilment of the requirements of the degree of

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A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of

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Of

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DEDICATION

This thesis is dedicated to my parents, Sofia and Yosyp, for their unconditional love and support. They have inspired me by their example to always give my best, assured me I can do anything I set mind to, and stood beside me in my every endeavor.

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PREFACE

What can be done to make this world better?

My background and personal family history has definitely had a decisive impact on my perception and approach to this paper. My career and education as a pharmacist has given me a broad insight into various aspects of the medication field from scientific and practical perspectives. My work at several community pharmacies allowed me to meet thousands of patients as they obtained their prescribed medicine and asked many different medication related questions. Yet, there was one experience that started to change my understanding of the patient's role in healthcare. My father, who had never taken any medication in his life, was diagnosed at age 69 with a common condition for elderly men-Benign Prostatic Hyperplasia (BPH). He was then prescribed his first medication. Three months later he was diagnosed with kidney cancer. At this difficult time- for me as a daughter, the primary care giver, and as a pharmacist, I observed how this older adult perceived his therapy. I recognized how little professional pharmacists concern themselves with the perceptions of their patients. During my studies in the Faculty of Pharmacy in Lviv (Ukraine), there was no mention in the curriculum concerning the social impact of medication use. However, this seems to be an important missing area of expertise: that of the individual's own preferences and ways of thinking about their medication use.

ABSTRACT

This exploratory study is based on two assumptions. The first assumption is that the world we live in is socially constructed. The second assumption is that patient participation in healthcare decisions is essential. The patient, as the end-user of medications, needs to be involved in order to improve the quality of medication use.

Despite increasing attention to geriatric pharmacotherapy, there is little information available concerning the older adults' perspectives on the use of medications. Therefore, the aim of the study was to explore the attitudes and practices regarding medication use by two groups in the aging population: aging with a disability and aging into disability. A qualitative approach, using in-depth semi-structured interviews, was used. Ten individuals aged 65 years plus, who use five or more prescription and/or over-the-counter medication, and who reside in the community answered questions about their experiences using medication.

These findings indicated that older adults' expectations of their medications are grounded in the reality of their experiences, attitudes, beliefs and social or health care situations. The thematic framework developed from the data demonstrated that older adult's perceptions of medication use linked to five themes through activities that helped them confirm or modify their perceptions. The five themes are: knowledge and experience, relationship with health care provider, drug management, attitude and impact of medical condition/or disability.

It is hoped that this study will provide valuable knowledge of the unique concerns of the older adults in relation to the use of medication.

INTRODUCTION

Today, a major proportion of the population survives to old age and is capable of living independently in their own homes. Some older adults are healthy while others have different illnesses or health disorders caused by the normal aging process. In Canada, older adults who need assistance with basic activities of daily living often receive the help and support of government sponsored home care. However, this support does not always include help with medication. Older adults who live in their homes are responsible for purchasing and managing their own medication. On the other hand, those living in a nursing home may have help from trained healthcare personnel to help them with their medicines (Furniss, Lloyd & Burns, 1998).

Medication use by older adults is a complex field (Tsujimoto, Hasshimoto & Hoffman, 1989) as it is intended to decrease the impact of illness, increase the quality of life, and prolong the patient's life. However, many medications produce undesirable side effects complicating the medical treatment and decreasing the quality of life (Onder, Pedone, Landi, Cesari, Della Vedova, & Bernabei, 2002; Lawson-Matthew, McLean, Dent, Austin & Channer, 1995). Drug therapy is considered the most common and important form of medical treatment in the care of the older adults. Previous studies of medication use in older adults have described the high number of drugs used, inappropriate drug use, and hospitalization related to adverse drug reactions. These studies were often conducted in nursing homes or geriatric hospitals (Nikolaus, Kruse, Bach, Speacht-Leible & Schlierf, 1996).

With proper medication, older adults function more effectively and are able to remain in their own homes and live independently (Beers, Jones, Berkwits, Kaplan, & Porter 2005) so they can maintain satisfying and happy lives.

LITERATURE REVIEW

Although everyone is familiar with aging, defining it is not so straightforward. Aging has been defined as a collection of changes that leads human beings progressively to death (Meadwar, 1952). Aging can also be defined as a progressive functional decline, or as a gradual deterioration of physical function with age, including a decrease in fecundity (Partridge and Mangel, 1999), or as the intrinsic, inevitable, and irreversible age-related process of loss of viability and increase in vulnerability (Comfort, 1964). Human aging is associated with a wide range of physiological changes that not only make us more susceptible to death but limit our normal functions and make us more susceptible to different diseases (Gavrilov, Heuveline 2003).

In Canada, being old is typically defined as being 65 years or older which also used to be the general age of retirement. The World Health Organization (2006) defines 60 years as old and 80 years as oldest old, or very old.

The elderly population is rapidly increasing in most parts of the world (United Nations, 2002). In developed countries this is mainly due to the increase in life expectancy, improved health and health services, as well as better diagnosis and treatment of disease which was earlier considered terminal (Raleigh 1999). The developed countries have experienced this growing population group for decades, while the phenomenon is new for the developing countries. The world's population of persons aged 80 years and older is expected to increase from 70 million in 2000 to almost 400 million people in 2050. Seven out of ten of the world's older adults are expected to live in developing countries (UN, 2002).

Population aging has many important socio-economic and health consequences, including the increase in the old-age dependency ratio. It presents challenges for public health (spiraling health costs are challenging a country's economic and social structure) while stunting economic development (shrinking and aging of labor force, possible bankruptcy of social security systems) (Rosenberg, Moore 1997).

Every older Canadian is a unique individual, but there are some things that statisticians know about the aging population as a group. One typical example is that women in Canada tend to live longer than men. At the present time, women represent 60 % of the senior population. At age 65 a woman can expect to live another 19 years whereas a man can expect to live another 15 years. Reasons for this are still unknown. Some argue that women are biologically superior. Others suggest that men experience greater stress in their lives, and still others that women are simply better at handling stress, especially emotional stress (Lindsay, 2000).

There is still have much to learn about the special problems of aging. It is known that the elements of life that contribute to personal happiness are common to both younger and older people. Good health, good relations with family and friends, and reasonable financial security all help to ease the adjustments that aging requires. The growing number of older adults in Canada represents a new phenomenon (Lindsay 1999). Today's seniors will shape and define a role for those who retire tomorrow. Diversity is the key word when talking about older Canadians. Some are married, some divorced, some widowed. Some live in urban areas, some in rural areas. Some are 65, some 95 (Lindsay, 1999). Because they differ so much in their situations and lifestyles, they differ in their needs. To provide services for the older adults in the fields of housing,

traditional medical services and community social services, and to meet those needs through the widest range of options, can be challenging.

Therefore, for the purpose of this paper aging will be defined as a dynamic, interactive process that promotes both personal behaviors and life-course environments that limit functional declines, especially those caused by chronic conditions and disability, thus helping older adults maintain their independence and health. "Aging well" emphasizes the idea that people can maintain satisfying and healthy lives as they age by exercising the choices that optimize healthy, active, and secure lives (Lindsay 1999).

Disability is a normal part of the human condition. Some people are born with a disability others develop a disability through the course of life owing to an accident, illness, and aging. Still others have disabilities that re-occur through their lives. Many people experience more than one condition that could be considered a disability. Disability occurs as a result of the interaction of health conditions such as disease or injury, personal factors such as age, gender, cultural identity, and one's social environment (Bigby, 2002).

The world "disability" encompasses a wide range of meanings and very often the people who supply the definition are not those who will have to deal with its implications. There is no single, unified and accepted definition of disability (Bigby, 2002).

Medical and social models of disability are of most concern. The medical model views disability primarily from the perspective of health conditions, and emphasizes rehabilitation, restoration, or repair of an abnormality or defect (Robertson, 1997). The medical approaches tend to focus on deficits rather than capacities. Thus, there is also less emphasis on the individual's capacities to function in his or her social and physical environment. Some theorists

have argued that disability is increasingly conceptualized as a medical problem (Robertson, 1997).

The social model views disability as society's failure to meet the needs of an individual with a disability, and to recognize his or her inherent rights as a human being. The social model of disability portrays the experts of disability as those who have lived the experience (Oliver, 2004 & Finkelstein, 2004). Oliver (2004) writes,

"The social model turned our understanding of disability completely on its head and argued that it was not our impairments that were the main cause of our problems as disabled people, but it was the way society responded to us as an oppressed minority" (Oliver 2004, p 7.).

The importance of the social model of disability is in helping understand the definition of disability itself. The social model stresses empowerment, participation and leadership of people with disabilities in effecting change.

In 1980 the World Health Organization (WHO) presented the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This was the first major classification system to focus specifically on disability. According to the ICIDH, disability is any reduction or lack of ability, caused by impairment, to perform an activity in a way considered normal for a human being (ODI, 2003). The federal government often uses this perspective to provide disability statistics. In 1986 and 1991, statistics were provided using a well-known data source called the Health and Activity Limitation Survey (HALS).

In 2001 HALS was replaced with the Participation and Activity Limitation Survey (PALS). This survey became the main disability source for data related to employment, education, income, supports such as tax and financial measures, and access to housing, transportation, recreation, leisure, health care and volunteer activities. The definition of disability by PALS is based on the International Classification of Functioning, Disability and Health (ICF). ICF views disability as the interrelationship between body functions, activities and social participation, while recognizing the role of the environment as providing both barriers and facilitators. For adults aged 15 and over, disability in PALS is defined as a limitation in activity as a result of a health problem or condition. The following types of disabilities are included: seeing, hearing, speaking, mobility, agility, learning, cognition, psychological, pain and unknown (i.e., the type of limitation was not specified) (WHO, 2008).

In Canada, according to the 2001 PALS, an estimated 1.45 million seniors aged 65 and over, reported some form of disability. An estimated 573, 000 seniors (40% of all those with disabilities) had reported severe or very severe limitations. The majority of those seniors were women, reflecting women's longer life expectancy.

In 2003, the House of Common Subcommittee on the Status of Persons with Disabilities made a recommendation to publish a report called *Defining Disability* (2003). In this report disability advocates, academics, mental health representatives, and medical professionals presented their views on implementing a definition. This report stated that the definition of disability itself involved many issues.

"Many people argue there is no simple way of defining disability. One definition of disability that fits all circumstances may not be possible or even desirable. Disability is difficult to define because it is a multi-dimensional concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct,

disability is seen in terms of social, economic or cultural disadvantages resulting from discrimination or exclusion" (Defining Disability, 2003, p.39).

In the older population, disability has been defined as the inability to perform or complete particular tasks or roles that previously could be accomplished without difficulty or the help of another person (Verbrugge & Jette, 1994). The definition indicates a deterioration or reduction in ability over time. Disability can also be defined as a difference or gap between an older individual's capability to complete a particular task and the demand required by this task (Verbrugge, 1990). The disability gap may be reduced by decreasing the demand of the task. For example, ramps or elevators can be used in place of steps, and living arrangements can be adjusted to decrease the individual's need to climb stairs. By recognizing and implementing changes where needed, older adults with disabilities can maintain an active life tend to be healthier, live longer, experience less disability, and lead independent lives (Guralnik & Simonsick,1993).

Most disability begins at older ages, and durations for older adults are rather short. This is known as disability into aging. Those who survive to late-life in community contribute to long durations are defined as aging with a disability (Verbrugge, 2002). Some researchers argue that there are distinct issues for people with early onset disabilities. These people have different life experiences from non-disabled people (lack of social support, an employment history, and in some cases pre-existing high dependency (Bigby, 2002, p.232). Older adults often see impairment as a normal part of aging and do not tend to think of themselves as disabled (Priestley, 2003, p.155). So the experience of someone who acquires disability with age is perhaps different.

A major concern about old age, for both the individual and society, is the decline in health. This can mean a loss of self-sufficiency and independence. With age, health declines and for the majority of seniors the loss happens gradually, and people learn to adapt to the changes. Because the problem of rising health care costs is rising fast, the increasing number of older adults may place an extra burden on the Canadian health care system. When we talk about the "health" of seniors, much of that assessment is based on survey information collected by the Canadian Community Health Survey (CCHS, 1999). Actually, only a small proportion of seniors (approximately about 20%) are heavy users of formal health services. Most do not use the health care system more than younger adults. A large number of older Canadians suffer from one or more chronic conditions, ranging from arthritis to eye problems. However, for the most part these do not prevent seniors from leading normal lives (CCHS, 1999).

According to the data of the CCHS, the most prevalent chronic conditions among women 65 to 74 years of age in 1999, were arthritis, high blood pressure, nonarthitic back problems and nonfood allergies. The next most prevalent conditions were cataracts and heart disease. The pattern was similar among men. The evidence from the CCHS suggests that most of older adults are in good health or have a perception of being in good health, having adapted to health conditions. However, there is a minority of 20% who are heavy users of the health services, especially among those aged 75 years and over, who have chronic health problems and/or are disabled.

Both the health status and utilization patterns of Canada's seniors raise many questions: how new physicians and other health care workers are being trained and how provincial health care systems are being restructured and need to be examined. It has been suggested that as life expectancy increases, the number of disability-free years will increase (Wilkins, 1986), and no one can predict what breakthroughs might occur in medical science. Besides the chronic ailments mentioned above, probably the most common fear of old age is a loss of mental faculties. Although there is no conclusive evidence of a dramatic decline in intellectual functioning or memory due to age, loss of hearing and sight among older adults can create the appearance of mental confusion. Alzheimer's disease, the most common type of dementia, affects only 6% of older Canadians; it sometimes seems more prevalent because there are now more seniors in society (Lindsay, 1999).

Health is partly physical, but to a degree also depends on how people feel about themselves. Most seniors view their health on the whole as good or excellent; however, expectations do vary from person to person. There are gender differences regarding health among seniors. Women report more symptoms than men and they tend to view their health quite positively. Both men and women gain at least part of their sense of good health from being able to continue to cope with life in the community, and from being able to maintain a secure and comfortable lifestyle. They often need more long-term care rather than expensive, short-term medical intervention (Knight & Avorn, 2001).

Canada's health care system is mainly designed to provide medical treatment for acute short-term illness or emergencies. Physicians are responsible for patient visits, prescribing medication, ordering medical tests, and controlling admission to hospitals. Hospitals provide short-stay medical care. The system is not geared towards support services for those who need help to live on their own. Therefore, a substantial effort was made in the 1970s to develop home health care and community support programs. Today many provinces offer a variety of services for seniors (Lindsay, 1999). Geriatric medicine differs from conventional medicine in a number of ways. When individuals get older, they tend to use more drugs (Giron,Claesson, Thorslund, Oke, Windblad, & Fastbom, 1999; Beers, Jones, Berkwits, Kaplan & Porter, 2005). Most of the drugs used by older adults are taken for years, usually to control chronic disorders such as diabetes, high blood pressure, and asthma. Sometimes drugs may also be used for preventative measures or for relieving symptoms and can be taken for a short period of time. A good example is to treat infections or relieve constipation.

Older adults are a major consumer of drug therapy, using considerably more drugs than the younger population (Rumble & Morgan, 1994). In Manitoba the proportion of the population aged 65 and older was 13.5% of the population overall in 2001. Ninety seven percent of those 65 year and older are on prescription medications and forty five percent received drug benefits under Provincial Drug Programs for all prescription drugs dispensed in a province for the last year (DPIN, 2007).

Medical treatment among the seniors is challenging. The common problems associated with use of medication by older adults include noncompliance, polypharmacy, under medication or omission, use of over-the-counter medications and alcohol consumption (Zhan, Sangl & Bierman, 1996).

Noncompliance may be detected subjectively by patient interviews, pill counts and refill records, or more objectively by monitoring serum levels and urine assays to measure drug metabolites. Compliance rates in patients taking long-term therapy can range from 40 to 60 percent. Poor compliance can have serious clinical consequences. If not recognized, non-compliance can increase both the patient's risk and healthcare cost, since physicians may increase the dosage or prescribe additional medications (Zhan, Sangl, & Bierman, 1996).

Drug management among older adults is complicated because of the high number of drugs taken. This is often referred to as polypharmacy. There are various definitions of polypharmacy. WHO defines polypharmacy as the concomitant use of five or more drugs (WHO 1985). Another definition of polypharmacy is the use of five or more prescription and/or overthe-counter medications (Veehof, Stewart, Haaijer-Ruskamp & Meyboom-de Jong, 2000). Studies of elderly people age 80 years and older have shown that the number of drugs has increased during the last two decades from three to five among those living in the community and from three to ten among those living in nursing homes (Giron, 1999). One explanation for this increased drug use is that new drugs have been introduced promising new possibilities for treatment of diseases.

Inadequate dosage or omission of an appropriate prescription is another common problem. Inadequate dosage has been reported with calcium supplements, transdermal nitroglycerin and bronchodilators. Frequent omissions include iron supplements in patients following surgery, cholesterol-lowering agents, oral hypoglycemic agents and bronchodilators (Rumble & Morgan, 1994).

Study results show a few factors related to increased medication use in the elderly. Some of those factors are impaired physical function, chronic diseases, poor-self-image, female gender, poor quality of life, living alone, depression, and smoking (Chrischilles, Foley, Wallace, Lemke, Semla, & Hanlon, 1992; Rumble & Morgan, 1994; Jensen, Dehlin, Hagberg, Samuelsson, & Svensson, 1994).

Medications can have desired effects and adverse effects. Older people are more than twice as likely to have side effects from drugs as young people (Beers, Jones, Berkwits, Kaplan & Porter, 2005). As well, in older adults, side effects can be more severe, requiring frequent visits to the doctor or hospital stays (Onder, Pedone, Landi, Cesari, Della Vedova & Bernabei, 2002).

As the number of older adults increases there is possibility of increasing disease occurrence. Old people sometimes are difficult to assess and to treat effectively, and are more vulnerable to medication-related errors. Therefore, understanding and predicting clinically agerelated changes in drug disposition would be a big help in medical treatment for the elderly to avoid adverse drug reactions (Tsujimoto, Hashimoto & Hoffman, 1989a).

Age-related loss in physiological capacity contributes to the decline in physical function in older adults (Cress, Buchner, Questad, Esselman, deLateur, & Schwartz, 1992). The functional ability of older individuals is important as it is an indicator of how well they cope with the activities of daily living, which in turn affects their quality of life. Functional ability can be defined as a person's ability to perform activities necessary to ensure well being (WHO, 1998). Disabilities or impairments, such as reduction in vision, hearing, understanding or capacity to move, may result in increased difficulty in performing common tasks, and may therefore create problems for older adults to remain living in their own homes (Fillenbaum, 1996).

The physical capacity of older persons is also important for the administration of medications. For example, in order to get prescribed medicine, the older person may have to walk to the pharmacy. To open packages of medications requires the functional ability of the hands. Without these skills the person would be dependent on others in helping them take their medications. Therefore, adequate health and functional ability are necessary for maintaining independence in later life, because these characteristics relate to the capacity to meet the needs of daily living (Mitchler & Burr, 2003).

Among older adults functional ability varies considerably: after the age of 85 the majority need some assistance with instrumental activities, and a portion of frail older adults are severely disabled (Spillman & Pezzin, 2000).

The population is aging across Canada. One important but less publicized trend about aging populations concerns people with disabilities.

Generally the older adults and people with disabilities are often considered as two discrete groups. In reality, there is a very large overlap among these two groups. According to Statistics Canada (2003) there were 259,500 Manitobans who were seniors (age 55+) and 163,340 Manitobans with disabilities. The overlap group of seniors with disabilities was 91,070 individuals. Among Manitobans with disabilities, 56% are seniors. As the population ages the size of the overlap group will increase significantly. More than 2/3 of all Manitobans with disabilities (68%) will be seniors in 2026.

National Population Health Survey (NPHS) data show that with increasing age, older adults use of hospitals and home-care services and of medications (prescription and over-thecounter drugs) increases. In the long term, Canada's total population is estimated to be about 41.2 million in 2031 (Statistics Canada), of which the older population will account for 8.9 million. Ultimately, this raises the question of meeting the growing demand of our older population especially older adults with disabilities.

Even if we are optimistic about future events, the sheer growth in the absolute number of older adults will present a major challenge to the people responsible for providing health care.

Medication Use by Older Adults

This section reviews the existing literature in order to gain some understanding of the perception on the use of medication in aging population.

Historical Context:

The vast majority of research examining medication use is centered on clinical trials and quantitative approaches. Only a small number of qualitative studies (Benson & Britten, 2002) are available. For the last thirty years, although many variables have been identified that are relevant to the extent and determinants of compliance with medication, few studies have successfully probed the predictability of adherence (Vermiere, Hearnshaw, Van Rooyen & Denekens, 2001). Reported studies have been of methodological quality, fragmented, and lack a theoretical framework but have provided insights into the constant comprehension of the concept of adherence. Blaxter and Britten (1996) found that older adults view medications as a resource to be used as needed, rather than as prescribed by the health care provider. Additional lay beliefs on medication use include: positive experience of communication with the prescriber (Benson & Britten, 2006), balancing fears with perceived benefits of taking medication (Benson & Britten, 2002), the need to reduce the symptoms of illness, to feel physically better (Kjellgren, Svensson, Ahlner & Salijo, 1998; Ekman, Anderson, Bowman, Charlsworth, Cleland, Poole-Wilson & Swedberg, 2006), fear of complications, and a desire to control symptoms (Svensson, Kjellgren, Ahlner & Salijo, 2000). The focus of future studies may wish to address medication use behavior in older adults. These studies preferentially selected older adults for several reasons. First, older adults are highly likely to suffer from multiple medical conditions (Hughes, 2004). Second, older

adults often take three or more prescribed medications concurrently to manage these conditions, and, third as a result of polypharmacy, older adults are increasingly likely to mismanage their medication regimes (Cortlett, 1996). Medication mismanagement is a significant problem as it can lead to poor control of chronic conditions such as heart failure (Cline, Bjorck-Linne, Israelsson, Willenheimer & Erhardt, 1999), hypertension (Mancia, Sega, Milesi, Cesana & Zanchetti, 1997; Benson & Britten, 2002), and cholesterol mismanagement (Senior, 2004).

Research has long established that drugs may cause or contribute to negative adverse events, such as significant morbidity and increased health care costs by increasing health care utilization (Atkin & Shenfield, 1995; Hanlon, Schmader, Koronkowski, Weinberger, Landsman & Samsa, 1997). Studies have reported non-compliance or non adherence rates in the aging population from 26% to 59% (van Eijken, Tsang, Wensing, de Smeth & Grol, 2003). One study by Ruscin and Semla (1996) showed that, in a sample of older adults with an average age 80 years, 22% of those who were physically dependent, and one third of those who had cognitive impairment, were still responsible for taking their own medications.

Knowledge and Experiences:

Studies of older adults' knowledge of medications have found more than 50% knew the names and purpose of their medications, however less than 25% knew the consequences of side effects (Barat, Andreasen & Damsgaard, 2000; Blenkiron, 1996). For example, one study of elderly patients with congestive heart failure found that, 30 days after a new medication was prescribed, only 64% of the patients could identify when they were supposed to take that medication (Cline, Bjorck-Linne, Israelsson, Willenheimer & Erhardt, 1999). Similarly, older adults were found to have insufficient knowledge of inhaler technique and how medications can

improve their asthma (Pinto Pereira, Clement & Da Silva, 2002). Noncompliant patients on anticoagulant therapy were more likely to report they did not know why their medication was prescribed (Arnsten, Gelfand & Singer, 1997). In a study of over-the-counter (OTC) medication use, few older adults knew precautions related to the OTC drugs they were taking (Conn, 1992).

Patient knowledge of drugs is seen as positively associated with adherence (Ogedegbe, Harrison & Robbins, 2004). Adherence to medication is considered a coping strategy used by elderly adults in response to a chronic medical conditions. Within this strategy, patients may recognize their perception of illness and how they self-manage the condition (Leventhal, 1992). The perception of a medical condition can be influenced by issues of disease etiology and duration, control or cure and its outcome, all of which can impact on adherence with medication.

Several reasons indicate why older adults may fail to adhere to prescribed medication regimens. Sale, Gignac and Hawker (2006) reported that older people were fearful of becoming addicted to their medication citing a concern about codeine based analgesics. Because of this, older adults often decided to take medication at the lowest possible dose, rather than prescribed by the physician.

Medication rationalization is not unusual for older adults. Similar findings emerged in a study examining hypertensive therapy in hypertensive patients (Benson & Britten, 2006). This study showed that patients' responses were a reflection of individual perceptions of their illness and the role of medication in its management. Individuals had a fragmentary understanding of the purpose of medication in their condition (Kjellgren, Svensson, Ahlner & Salijio, 1998). Older adults, more at risk of developing adverse reactions to drugs, were those on long-term medication regimens (Veehof, Stewats & Meyboom, 1999). In addition, age can have an influence on adherence to medication regimes. Individuals over 75 years of age take more

medications than individuals in the 65-74 year age group (Chen, 2001). Some adherence risk factors are: inability to manage medication use (Griffiths, Johnson, Piper & Langdon, 2004), uncomfortable and bothersome medication adverse effects (Kippen 2005), cognitive impairment (Salas, Int'Veld & van der Linden, 2001), lifestyle changes that are caused by travelling, and social events (Stevenson, Kjellgren, Ahler & Saljo, 2000). Another study showed that adherence to medication was associated with knowledge of beneficial effects of medication and the possible complications of non-adherent (Unson, Siccion, Gaztambide Mahoney Trella & Prestwood, 2003).

The relationship between patient's medication knowledge and adherence is articulated by the multi-factor model of adherence developed by Park (Park & Jones, 1997). According to this model, adherence depends on cognitive abilities, medications and disease variables that influence beliefs about illness and treatment. Age primarily influences adherence through cognitive function. Thus, comprehension and other components of adherence may be compromised by age related differences in working memory (Park & Smith, 1996) and health-related literacy (Barker, Gazmararian, Sudano & Patterson, 2000).

Canada, the United States, and Australia are among the countries that have delved into the issue of patient safety by researching the concept of adverse events (Baker et al., 2004; Brennan et al., 1991; Wilson et al., 1995). Adverse events, as defined by Baker et al., (2004), are "unintended injuries or complications resulting in death, disability or prolonged hospital stays that arise from health care management" (p.1678). Therefore, depending on the effect on the patient, process errors in medication administration could result in adverse events. Attitude towards medication use:

The use of medication in a concept of adherence and non-adherence has been broadly examined (Bonner & Carr, 2002; Kjellgren et al., 1995; Phatak & Thomas, 2006; Roth & Ivey, 2005). Table 1 presents common perceptions and characteristics of adherent and non-adherent medication taking behavior (Phatak & Thomas, 2006).

 Table 1: Common perceptions and characteristics of adherent and non-adherent medication use behavior

Perceptions related to the use of medication	Intentional non-adherence	Non-intentional non-adherence
Past experience of medication	Recognition/anticipation of side effects	Forgetfulness
Long term risks of medications	Lack of faith in prescriber	Disruption to daily routine
Adverse effects of medications	Failure to accept illness	Altering dosing regimen
Lack of knowledge of the purpose of medication	Perception of health risk	Duration of illness

Individuals with adherent medication-taking behavior tend to use their medication according to purposeful or pattern medication regimens. Older adults have the ability to reinforce adherence with use of compliance packages and pill boxes.

In relation to non-adherence with medications, two different patterns are identified: purposeful or intentional non-adherence and accidental or unintentional non-adherence (Johnson et al., 1999). Those two types of non-adherence relate to the lack of an established pattern of medication use which led to the incidental error in taking medication (Johnson et al., 1999). Patients' perceptions about medication may be based on their past experience with medications, and long-term risks of medication (Benson & Britten, 2002) such as drug-related memory loss and dizziness (Lumme-Sandt, Hervonen & Jylha, 2000) as well as the understanding of side effects of medication (Hughes, 2004; Kippen, Fraser & Ellis, 2005). Intentional non-adherence is caused by the anticipation of drug-related side effects (Lumme-Sandt et al., 2000). Individuals who share their medication-taking concerns and fears with their physicians often benefit by receiving appropriate intervention such as additional explanations of either the medication they take, or of a change of dosage (Butler, Arbogast, Belue, Daugherty, Jain, Ray & Griffin, 2002).

The perception of risk related to a medical condition also correlates with intentional nonadherence with medication. Sometimes older adults use medication in relation to the necessity of treatment, potential side effects, and the purchase of affordable alternatives (Unson et al., 2003). Non-adherence patterns in older adults also revolved around issues related to perceived drug benefit, drug safety and efficacy, and ability to improve health (Benson & Britten, 2002).

Non-intentional adherence in older adults is based on cognitive impairment (forgetfulness), life style changes, disruption to daily routine, duration of illness and being asymptomatic (Svensson et al., 2000). Older adults adherent to their medication often link the use of medication to specific lifestyle events, time, location and patterns of daily activities (Svensson et al., 2000; Kippen et al., 2005).

Within the wider literature on adherence, there is evidence to suggest that patients' treatment and illness beliefs have an important influence on their decisions about treatment (Sewitch, Abramovicz, Barkun, Bitton, Wild, Dohen & Dobkin, 2003) and that many people have fairly negative or ambivalent views of medications (Townsend. Hunt & Wyke, 2003).

Drug management:

There is a wide variety of factors that place older adults who live in a community at risk for problems in medication management. Those aged 66-74 years have been found to be more adherent to medication regimens than middle-aged adults, but after age 75, older adults present decreased comprehension of medication instructions and adherence (Raji, Kuo & Salazar, 2003; Segal, Tamir & Ish-Shalom, 2003). Living arrangements influence the older individual's ability to manage medications, and older adults who live alone were found to be more prone to medication errors (Salas, et al., 2001; DiMatteo, 2004). This is exacerbated by the fact that there is no one to monitor, assist, or remind the older person about taking their medications. One of the challenges in the reconciliation of medications is determining exactly what medications older adults are taking in their home. One study found 49% of older adults kept stores of old medications and 6% admitted they self-prescribed medications on at least one occasion (Tamblyn, McLeod & Abrahomowicz, 1996). Multiple studies have demonstrated that 10-74% of medications prescribed for older adults were inappropriate (Bloom, Frank & Sharif, 1998; Tamblyn et al., 1996; Zhan, Correa-de-Araujo & Bierman, 2005).

Poor vision and low manual dexterity are associated with poor medication selfmanagement (Ruscin & Semla, 1996; Atkin, Finnegan & Ogle, 1994). The inability to read medication labels has been associated with non-adherence to long-term medications among older adults (Lile & Hofman, 1991). One study found 28% of community-based older adults kept their medication bottles only partially closed, so that they could more easily open them, and 47% admitted that labels on their medications were unclear and they could not read them due to poor eyesight, inability to read English, or small writing on the label (Tamblyn et al., 1996). Another study reported that from 31% to 64% of older adults living at home have difficulty opening medication containers, with childproof containers presenting the most difficulty (Atkin et al., 1994). Medication-container modification is one area of intervention for older adults who have difficulty opening or reading containers. Use of non-childproof containers is one option for older adults, and compliance packaging has resulted in increased compliance of medication use. (Murray, Birt & Manatunga, 1993). Different tablet formations, designed to increase the ease of breaking tablets, have been found to impact patients' abilities to comply with their medication regimen (Wilson, Kassier & Morley, 2001). Several studies have demonstrated that dose simplification from two times a day to one time a day produces higher compliance and improved patient outcomes (Andrejak, Genes & Vaur, 2000; Dezii, 2001; Claxton, Cramer & Pierce, 2001).

Children, and other relatives, of aging adults provide about 80% of all care, and these informal care providers provide three times as much direct care for elders as do all nursing homes, hospitals, and other institutions combined (Perlman, 1983). Medication assistance is becoming a more prevalent aspect of care-giving (Brodaty & Green, 2002; Smith, Francis, Gray, Denham & Graffy, 2003). A recent survey of long-term caregivers found that 48% of caregivers helped with medications (Donelan, Hill, Hoffman, Scoles, Feldman & Levine, 2002). These types of care providers are an often overlooked resource to assist with medication compliance problems among elderly adults. A study of family caregivers' medication administration experiences reported that administration issues and concerns were consistent with the frustrations and stresses of daily hassles found in the care-giving literature (Travis, Bethea & Winn, 2000). In one study, medication-related tasks accounted for 7.7% of the total care-giving time, yet they contributed to caregivers' stress, with 32% of caregivers reporting problems directly related to

medications and 19% and 52%, respectively, reporting problems in managing the drug regimen in the current or past year (Rannelli & Averda, 1994).

The Institute of Medicine's (2000) report To Err is Human: Building a Safer Health System strongly recommended that patients be viewed as members of the health team and encouraged to become actively involved in their own care. Vincent & Coulter (2002) reported, that patients are usually perceived as victims of errors and safety failures, when in fact they view active involvement or partnering in their care as their responsibility. Safety promotion can be enhanced when patients participate in the various stages of their care: reaching an accurate diagnosis, determining an appropriate treatment plan, choosing experienced providers, ensuring treatment is appropriately administered, monitored and followed, and identifying side effects or adverse events quickly (Vincent & Coulter, 2002). Engaging patients in providing their perspective on safety practices and their participation/accountability in care is a vastly under researched topic. The safety literature recommends that patients become active participants in the delivery of their care. Understanding the patients' perspective on this issue could guide healthcare providers in evolving the system to support the shift to active patient participation. It would be important to explore patients' perceptions regarding their active participation and accountability as medication consumers; the results would be useful in filling a gap in the current body of literature.

Acceptance of illness/or impairment and impact on medication use:

About half of the drugs prescribed for patients with long term conditions are not taken as prescribed (Haynes, McKibbon & Kanani, 1996). This non-adherence has been described as a "serious deficit at the core of medical practice, with consequent massive personal, societal, and

economic cost" (Marinker & Shaw, 2003). Haynes et al. (1996) emphasized the need for a better understanding of non-adherence and noted that, "With the astonishing advances in medical therapeutics during the past two decades, one would think that studies on the nature of nonadherence...would flourish." However, few studies of users' views of drugs have been published, especially when one examines the extensive literature on lay beliefs about medical conditions (Britten, 1996). Studies of patients' ideas about prescribed drugs have focused on people with specifics conditions (Benson & Britten, 2002), or on samples recruited through general practice (Bitten et al., 2002).

A patient's past experience of medication use can adversely affect their adherence to medication (Britten et al., 2002) and can lead to motivation of taking medication (Benson & Britten, 2002). Such a statement is often related to deficient comprehension of the purpose of medication in illness management and poor acceptance of their illness (Phatak & Thomas, 2006). Therefore, it is important that patients understand their medical conditions, the role that medication plays in the management of the symptoms of that condition and address the personal challenges of use of their medication (Dowell & Hudson, 1997).

The older adult's decision making process can also affect adherence to medication. Three phases are identified: individual knowledge about the medical condition and proper treatment; testing of medication and medication management (Dowell & Hudson, 1997). Belief in the physicians' ability to properly diagnose and manage their illness is vital (Levy & Feld, 1999; Unson et al., 2003). Testing the clinical effectiveness and side effects of medication is often undertaken and usually involves omitting or discontinuing medication before developing a regular adherence pattern and fully accepting the need for medication (Dowell & Hudson, 1997). Because side effects of medication may be viewed as being worse than the medical condition, all

new medication needs to be carefully explained to patient (Barber, Parsons, Clifford, Darracott & Horne, 2004). Many patients consciously choose not to fill a prescription, do not take their medication as prescribed, or discontinue therapy (Finsham, 1995). These choices are influenced by a number of factors related to patients' past experiences, their understanding of their illnesses and can include: perceptions about the nature and severity of their illnesses, the assumption that once the symptoms improve or they feel better, they can discontinue the use of a medications, limited appreciation of the value of the medication when properly used, belief about effectiveness of the treatment, worries about social stigma associated with taking medication, fear of side effects, and lack of confidence in the ability to follow the medication regimen.

The third aspect of medication taking behavior relates to acceptance of an illness/or impairment (Dowell & Hudson, 1997). Three groups of medication users are identified. Passive users take their prescribed medication and usually do not question the purpose of the medication. Active users adjust their medication intake according to their personal needs and have interest in the medication they take. The third group called rejecters, are those individuals who fail to adhere to their medication regimen (Dowell & Hudson, 1997). By examining older adults' views and potential misconceptions about their illness/or impairments, physicians can assess their willingness to take medication as prescribed that are important to successful medication management.

Relationship with health care provider:

In examining medication non- adherence, one of the most significant factors related to the prescriber are lack of time and poor communication skills. One study examined the concerns of older adults with diabetes concerning the complexity of their medication regimens and whether they discussed medication-related concerns with their physicians. One of the findings was that many older adults did not think it was appropriate to discuss their concerns about medication costs with their physician or doubted that chronic illness medications were necessary at all (Tjia, Givens & Karlawish, 2008).

The older adults communication with their health care providers should be friendly and not rushed, as an open discussion that can provide an opportunity for patients to ask questions about their illness and prescribed medication. This is often not the not case (Watson, Mitchell, deCrespigny, Grbich & Biggins, 1998). During the visit with their doctor, older adults need to participate in shared medication-specific decision making in a language and style to which they can relate (Veehof et al., 1999). This approach is very important to determine the appropriate medication use of older adults (Svensson et al., 2000; Benson & Britten, 2002). In some cases, older adults were confused by incomplete and unclear instructions on how to take prescribed medication. For example, patients were told to take a medication at a particular time of the day, with no explanation of what could happen if they would not follow the instructions. The discrepancies in the information provided by different health care providers also led to confusion for the aging patients (Kippen et al., 2005).

Research and anecdotal evidence have supported the health care provider's view that social factors and the patient's individual personality significantly affect how the long-term consequences of the medical condition are managed by the patient themseves (Jenkinson, 1994). These views enable all health care providers to justify some patients' failure to cope. It is possible that patients' poor self-esteem, loss of hope and fear, reduce their ability to be assertive and seek the support that they need. Equally, they may feel that individuals seen as "sick" or
with a "chronic disease status" have been identified as having poorer value in society (Greer, 1991).

Current research has identified the need to empower the patient, and suggests that this can result in not only informed and effective decision making but also in a significant improvement in patient satisfaction and treatment compliance (Holman & Lorig, 2000). A good doctor-patient relationship is seen as an important component in the patient's ability to cope, yet there remains a disparity between perceptions and expectations during consultations (McKinley & Middleton, 1999). Doctors have been shown to be poor predictors of patient needs (Williams, 1989). Some patients value explanation and continuity of care over technical interventions and competence (Scott & Pill, 1990).

However, it is simplistic to conclude that a better outcome can be achieved purely as a result of an improved doctor-patient relationship. Psychological and social research has identified a range of behavioral factors that individuals deploy when receiving health care intervention (McCann & Weinman, 1996). An important component in the patient's ability to cope is that of their relationship with their family doctor and the level of support they perceive as available to them.

Healthcare providers need to be aware of the complex perceptions that older adults hold, in order to develop a mutually trusting relationship with their patients. Patients have invested a significant amount of their medical condition experience with their family doctor and wish to build and maintain a trusting mutual relationship with them. At a time when health care providers are expected to increase their pace, effectiveness and technological skills to manage the health care needs of their community, the danger is the least vociferous consumers may get left behind.

Summary

The literature gives some insights into the historical context, the knowledge and experience of older adults, their attitudes towards the use of medication, their acceptance of their medical condition as well as their relationship with their health care provider. However, within the literature on use of medications, one unexplored area is older adults' perceptions of use of their medications (*see page 24*). Perceptions may be an important factor in making decisions as to prescribe or use a medication. Disagreement between health care providers' and patient's expectations of medications can result in unintentional adverse drug events or unrealized health benefits for patients. Therefore, the question becomes what are the perspectives on the use of medication in aging population.

METHODOLOGY

Objectives/Research Questions:

This study focuses on how older adults view themselves as users of medications. The goal of this study is to examine how older adults living in the community, in their own homes, view their own medication regime management, medication taking, and related health behavior.

The research questions of the study are:

- 1. What attitudes do older adults have regarding medication use?
- 2. How do older adults reflect on their own experiences of drug management?
- 3. What perceived changes have older adults undergone as a result of their drug regimen?

These questions became "working guidelines" to explore the "experiences of individuals." The interview questions were open-ended to allow the participants to be fully engaged in the interview and encourage them to tell their personal stories.

<u>Research Design</u>:

According to Creswell (1998), qualitative research is "an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem" (p.15). He pointed out that qualitative researchers "strive for understanding" (p.193). It was important that the participants of a study provided information from their own "frame of reference" (Taylor & Bogdan, 1998). Face-to-face in-depth interviews were conducted with ten participants who spoke English and/or Ukrainian. This in-depth interviewing gave participants the opportunity to describe their experiences in their own words (Cormack, 2000). Bogdan and Biklen (2003) believe the in-depth interview to be appropriate when "the researcher is bent on understanding, in considerable details, how people...think and how they came to develop the perspectives they hold" (p3). As Seale (2004) indicates, in-depth interviews "are often used to encourage an interviewee to talk, perhaps at some length, about a particular issue or range of topics" (p.181). This format of interview has three important advantages. First, participants have the freedom to carry the discussion in the directions of their choice, which is helpful in exploring their personal experiences and feelings. Second, this interview design is flexible, and reflects emergent findings. Third, the interviewer becomes more of a recorder of the talk, rather than a director. Seale (2004) states that interviewing "is particularly useful as a research method for accessing individual attitudes and values things that cannot necessarily be observed or accommodated in a formal questionnaire" (p.182). The attitudes, values and personal experiences of the older adults are the key to understanding the issues they face regarding their medication use.

Ethical Considerations:

Approval for the study was obtained from the University of Manitoba, Joint Faculty Research Ethics Board (Protocol # J2008:133). All participants were asked to sign a Consent form (*see Appendix A*) and had the right to withdraw from the study at any time. At the completion of the study, data were coded and reported as group data to ensure participant confidentiality. The project did not involve deception of any kind. No honorarium was paid to any of the study participants. A copy of the ethic certificate is provided in Appendix D.

Participants:

To select the participants for this study a convenience sample method was chosen. To identify the older adults as participants, the following recruitment strategies were used: 1) individuals who had expressed interest in participation; 2) older adults age 65 and over who were taking five or more prescriptions and/or over-the-counter medications and who lived in a community; 3) five individuals with a disability or medical condition developed before age 65 and five individuals with a disability or medical condition developed after age 65. To recruit participants for this study, the researcher placed a poster advertisement in selected community pharmacies and medical clinics (see Appendix E). Community pharmacies and medical clinics were asked to place one page handouts on the counter for older adults to read. If they were interested in participating in this study they gave permission to be contacted. E-mails were sent to friends and a family with a brief description of the study and the purpose of the interview with a request, asking if they had any older adult family member who would be interested to participate in this research. As a result, four participants were recruited through community pharmacies, two participants through the Arthritis Centre and Multiple Sclerosis Clinic (both located at HSC), three participants from the Ukrainian community and one from word of mouth.

An overview of the participant characteristic is outlined in Table 2.

Characteristics	Description	Partic	ipants
		N	%
Age, mean ± SD	78.87 years, 2.5±.97		
Age range	60-69.99 years	2	20
0	70-79.99 years	2	20
	80-89.99 years	5	50
	90-99.99 years	1	10
Gender	Female	5	50
	Male	5	50
Education	Some high school or less	2	20
	HS graduate/or college	4	40
	University graduate	4	40
Marital status	Married	5	50
	Single/or divorced	1	10
	Widowed	4	40
Living arrangements	Spouse/family	6	60
	Alone	4	40
Number of prescribed	5-9	8	80
medications/OTC	10 or more	2	20
Disability/ or	Developed before age 65	5	50
impairment	After age 65 or in future	5	50
Self-reported health	Very good	1	10
status	Good	6	60
	Fair	3	30
Medical condition/	Diabetes	1	10
co-morbidities	Arthritis (RA) and (OA)	2	20
	Multiple Sclerosis (MS)	1	10
	Parkinson's Disease	1	10
,	Hypertension(HBP)/Heart	8	80
	Lung Disease (COPD)	1	10
	Glaucoma/WMD	1	10

Table 2: Participant characteristic (n-10)

In addition to the open-ended interviews, participants were asked some demographic and socio-economic questions to generate brief profiles of the study participants. This ensured that the same characteristics were collected for all participants.

Most of the participants were between the ages of 76 years and 86 years. The youngest was 65 years and the eldest 94 years. Five were married, four widowed, and one was single (never married). Four of the participants lived alone. The others either lived with their spouse/or children. Two participants had some high school education or less, four were graduates from high school or college and four were graduates from university. Their occupations included a teacher, architect, pharmacist, bank-teller, labor-worker, legal assistant. The gender demographic ratio of participants in the study was: one male to one female. The majority reported good health, although everyone reported having 1 to 4 of the co-morbidities (diabetes, hypertension, history of cardiovascular disease, congestive heart failure, rheumatoid/and osteoarthritis, chronic obstructive lung disease, glaucoma, wet macular degeneration, Parkinson's disease and multiple sclerosis).

Procedure:

As Patton (2002) states,

"There are no rules for sample size in qualitative inquiry. Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what is useful, what will have credibility, and what can be done with available time and resources (p. 244). A purposive sampling technique was used (Paton, 2002) for the overall selection of participants. Participants were not selected randomly, but rather on the basis of the characteristics and experiences they possess. This type of sampling is intended to select what Patton (2002) refers as to "information-rich cases for study in dept...from which one can learn a great deal about issues of central importance to the purpose of the inquiry..." (p.230).

Interviewees included five individuals (aging into disability), aged 65 and over, who were taking at least five prescriptions or/and over-the-counter medications, who resided in the community in their own homes. In addition, five individuals with disabilities (aging with a disability), aged 65 and over, who were taking at least five prescriptions or/and over-the-counter medications, who resided in the community in their own homes, volunteered to participate as well.

The interviews were conducted in a quiet setting of the participants' choosing where they felt safe and comfortable, and at a time convenient for them. Nine people were interviewed in their homes and one individual at an Arthritis Centre in the Health Science Centre (HSC). Prior to the start of interview, each participant was given a consent form that had background on the study and contact information. The consent form explained that there were no known risks to participants in this study, participation was voluntary and the participants would refuse to participate and withdraw from the study at any time. The participants all signed the consent before their individual interviews started (*see Appendix A*). The interview was audio taped using digital audio recorder and pseudonyms were used to maintain confidentiality (*see Appendix C for the interview checklist*). The interviews with the elderly individuals lasted approximately 30 to 60 minutes. Short notes were written during the interview. This was found to be particularly

helpful as a reference in a process of the transcribing all sessions. It also ensured an uninterrupted flow of conversation during the interview. Three interviews, at the request of participants, were conducted in Ukrainian. The researcher translated the transcription of each of those interviews to English. All the transcription tapes were kept in a locked, secure location and were destroyed at the end of the research. An interview guide and interview checklist was used during the course of the data collection *(see Appendix B and C)*.

Overall participants were positive. This could be attributed to a range factors, most notably self-selection. It maybe because that participants volunteered or because those who spoke Ukrainian felt happy to communicate in own language and it created a positive feeling. Or maybe they represented the world as it should be.

<u>Data Analysis:</u>

Marshall and Rossman (1999) state, that data collection and data analysis must be a simultaneous process in qualitative research. According to Merriam (1998) qualitative data analysis primarily entails classifying things, individuals, and events and the properties that characterized them. The focus of qualitative research is on participants' perceptions and experiences, and the way they reflect their lives (Merriam, 1998). The attempt, therefore, is to understand not only one, but multiple realities (Lincoln & Guba, 1985).

The grounded theory approach was chosen to do the data analysis in this study because these methods allow few directions, managing and streamlining of the data collection and, moreover, construction of an original analysis of one's data (Atkinson, Coffey, & Delamont, 2003). The following sections will describe the stages of data analysis in detail.

Stage 1:

In the first stage, the recorded interviews were transcribed in full and analyzed using thematic analysis. First, each transcript was broadly coded based on the study questions. This initial coding remained open to exploring whatever theoretical possibilities could be discerned in the data. Sharmaz (2006) indicates this initial step in coding moves the researcher towards later decisions about defining core conceptual categories. This method of coding of interview questions helped to find the main focus of a participant during the conversation. For example, the first question was "Please tell me about yourself." Each participant started his/her story differently. Some older adults began by talking about a medical condition or an impairment while others talked about family. The coding framework of the transcripts within each question is shown below in Table 3.

Subjects	Question 1	•••	Question 12
G1S1F	Medical condition/ impairment		
G1S2F	Family		
G1S3M	Family		
•••			
•••			
G2S5M	Medical condition/ impairment		

Table 3. Coding tramework within each auest	ework within each auestion
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This analysis helped to gain knowledge about what each participant viewed as important to them. Grouping of data by questions in stage 1 identified the following segments of data *(see Table 4)*.

Interview	Focus				
Question	Stage 1	-			
1	Medical condition/ impairment, family, work				
2	Living arrangements				
3	Information and familiarity with medication				
4	Interest in medications				
5	Purposes of medications taking				
6	Odd/bad experiences with medications use				
7	Drug management				
8	Help with medications				
9	Doctor's and pharmacy's visits				
10	Attitude				
11	Impact of disability/or medical condition				
12	Quality of life				

 Table 4: Stage 1 Question focus

The order in which the interview questions were listed remained constant for all participants. However, the order of presentation for analysis has been changed in order to show the theme grouping.

<u>Stage 2:</u>

In the second stage of analysis, the transcripts were grouped by theme. Eight themes emerged revolving around older adults' self-reflection on medication use.

For the purpose of this study, attitude was defined as a way of thinking, feeling or behaving with respect to medication use and/or challenges caused by aging with a disability and aging into disability (Rowe, 1998). Attitude influences an individual's choice of action and responses to challenges, incentives and rewards. A good, positive attitude can more than compensate for a number of things that may be lacking in a person's life. Positive attitude is related to greater satisfaction with life as one ages (Rowe, 1998).

Self-reflection is a term used to describe the process of examining the impact of personal values, beliefs, styles of communication, and experiences. One's sense of hope, humor and confidence determine the tone of one's experience (Rowe, 1998).

In this stage, the results were categorized according to the following themes: acceptance and perceived necessity of medications, information and familiarity with medications, medication fears and concerns, own activity in drug management, assistance with medications, relationship with healthcare provider, attitude towards medications use, and perceived impact of medical condition/or disability on medication use. Figure 1 represents the initial outline of the relationship of the above mentioned categories.





However, although the themes appeared on the surface to be different, some themes had underlining commonalities. Similarities existed in the following themes: 'acceptance and perceived necessity of medications', 'information and familiarity with medications', and 'medication fears and concerns'. These three themes had a common main focus which was "medication". Two other themes that shared the same main focus were: 'individual's own activity in drug management' and 'assistance with medications'. Those were grouped under "drug management". The outcome of data analysis in Stage 2 is summarized in Table 5. Therefore, the twelve questions focused on eight themes.

Interview Question	Original Focus(Themes) Stage1	Revised Focus (Themes) Stage 2
3	Information on medications	Information and familiarity with
4	Interest in medications	medications
5	Purposes of medications taking	Acceptance & perceived necessity of medications
6	Odd/bad experiences with medications use	Medication fears and concerns
7	Drug management	Own activity in drug management
2	Living arrangements	Assistance with drug management
8	Help with medications	
9	Doctor's and pharmacy's visits	Relationship with healthcare provider
10	Attitude	Attitude towards medications use
11	Medical condition/or impairment	Perceived impact of medical
12	Quality of life	condition/or disability
1	Medical condition/ impairment, family, work	Opening question

Table 5: Stage 2 Eight themes

<u>Stage 3:</u>

In the third stage of analysis, the eight themes that emerged from Stage 2 were examined for similarities and differences. Several themes overlapped: three themes 'information and familiarity with medications', 'acceptance and perceived necessity of medications' and 'medication fears and concerns' became the 'knowledge and experience' theme. These themes provided information about how older adults reflect their familiarity about medication they use and their experiences with medication taking. Knowledge about medication helps an individual to understand the idea about necessity of taking medication and therefore accept the 'medication' as an important aspect to maintain their health. Information on medication and familiarity showed the knowledge level about medication of each participant. Whether this is a bad or good experience, such as side effects or adverse effects the individual has to go through, it provided the idea of knowledge and experiences with medication use. Medication fears and concerns were also a reflection of older adults' experiences. Two themes 'own activity in drug management' and 'assistance with drug management' became 'drug management'. This statement is supported by the fact that both themes provided information about how to take medication and how to make arrangements for acquiring medication. The new framework is outlined in Table 6.

Table 6: Stage 3 Five themes

InterviewOriginal FocusQuestion(Themes)Stage1		Revised Focus (8 Themes) Stage2	Revised Focus (5 Themes) Stage3
3	Information on medications	Information and familiarity with	
4	Interest in medications	medications	Knowledge and
5	Purposes of medications taking	Acceptance & perceived necessity of medications	experience
6	Odd/bad experiences with medications use	Medication fears and concerns	
7	Drug management	Own activity in drug management	
2	Living arrangements	Assistance with drug	Drug management
8	Help with medications	- management	
9	Doctor's and pharmacy's visits	Relationship with healthcare provider	Relationship with healthcare provider
10	Attitude	Attitude towards medications use	Attitude
11	Medical condition/or impairment	Perceived impact of medical condition/or	Medical condition/or
12	Quality of life	disability	disability
1	Medical condition/ impairment, family, work	Opening	question

<u>Stage 4:</u>

Interview responses are seen not only as factual reports, but also as a means by which people can articulate their own position in the world, and provide an insight into how and why people present their view in the way they do (Silverman 1993). Accordingly, the focus of the analysis is on the focus of the responses.

In Stage 4, the themes of the theoretical model established in Stage 3 were further analyzed to determine the relationships with the overall theme of perception of the use of medication. For example, knowledge and experience about medications appear to have an influence on older adults' perception of use of medication. Therefore, the link between the two concepts became the word 'influence'. On the other hand, perception of use of medication seemed to be facilitated by drug management. The linking word between these two concepts became 'facilitate'. The participant mentioned that the healthcare providers nurtured them in the use of medication. As a result the linking word became 'nurture'. Individual's attitude determined individual's perception of use of medication, therefore the linking word became 'determine'. Finally, medication had positive effects and therefore the participants were able to acknowledge their disability/ medical condition. Consequently, the linking word became 'accept'. The relationships being made with the linking words are outlined in Table 7

In effect this stage defined the effect and affect of the use of medication. The information resulting from the data analysis is described in Figure 2.





Q Stage 1 Answer Focus		Stage 2 Revised	Stage 3 Revised	Sta Relat	Stage 5 Validity	
		Focus (5 Themes)	Focus (8 Themes)	Affect (Link)	Effect (Impact)	Check
3	Information/ familiarity with medication	Information/ familiarity				
4	Interest in medication	medication				
5	Purpose of medication taking	Acceptance and perceived necessity of medications	Knowledge and Experience	Influence	Fears Concerns Importance Necessity	100%
6	Odd/bad experiences with medication use	Medication fears and concerns	-			
7	Drug management	Own activity in drug management	Dura	Facilitata	Salf family	100%
2	Living arrangements	Assistance	Management	racintate	Other	10076
8	Help with medications	with medications				
9	Doctor's and Pharmacy's visits	Relationship with health care provider	Relationship with health care provider	Nurture by	Doctor Pharmacist	100%
11	Medical condition/or impairment	Impact of disability/or	Impact of disability/or medical	Accept	Quality of life, change	100%
12	Quality of life	condition	condition		or mestyle	
10	Attitude	Attitude	Attitude	Determine	Positive Negative Neutral	95%
1	Medical condition, impairment, family, work			Opening	question	

Table 7: Stage 4 Relationship with overall theme

Stage 5:

In the fifth and final stage of data analysis, the researcher re-examined field notes. interview transcripts and audiotapes, to ensure the data were "true" to the stated perceptions of those interviewed. An essential validation process in qualitative research is that of ensuring that the analysis is free from researcher bias and true to the data (Creswell, 2002). To minimize personal bias and ensure validity of the data, transcribed interviews were given to two separate independent individuals to analyze. Two individuals, one with a M.A. in Disability Studies, the other with a B.Sc. in Pharmacy, were asked to undertake validation checks. Both independently coded all transcripts according to the Interview Evaluation Guide presented in the Appendix F. Even though not required methodologically, this provided additional perspectives on how the participants' responses could be viewed and afterward categorized. "The validators" were asked to determine emerging themes for each older adult interview. A copy of the evaluating form provided to the validators is outlined in Appendix E. The researcher and validators then spent approximately three and half hours comparing and evaluating their responses. When responses were different (number 21, 27, 35 and 49) discussion took place until a consensus was reached as to agree or disagree. In all categories, discussion continued until a consensus was reached. Texts were compared with previously coded transcripts (confirmation on agreement 95%). The process also included agreement on emerging themes identified in the transcripts.

RESULTS

"Analysis finally makes clear what would have been the most important to study, if only we had known beforehand." (Patton, 2002)

The insights gained from the interview responses on how older adults present their view on the use of their medications according to the five themes developed as a frame work model in this study are described in the following sections.

Section 1

Demographics:

Among the ten older adults interviewed, five were females and five were males. The mean age of the subjects (n=10) was $2.5\pm.97$ year *(see Table 2)*. This shows that 50% of the individuals in the study group were in the age range 80-89. The oldest person was in the age range 90-99 years and the youngest in the age range 60-69 years.

Three males and two females had developed their existing medical condition/or a disability before age sixty-five. Two males and three females had developed some medical conditions, which lead at some point to disability, after age sixty five. According to this description (not including gender differences), all participants were divided in two groups: Group 1- aging with a disability and Group 2 - aging into disability.

The descriptive statistics showed slight differences between these two groups. The average age of an individual in Group 1 was 73.60 years, where the average age of an individual in Group 2 was 84.13 years. The average age among all males of both groups was 76.34 years and the average age among all females of both groups was 81.40 years. The average age among all participants was 78.87 years (SD \pm .97).

Individuals in Group 2 took slightly less over the counter (OTC) and prescription medications than individuals in Group 1. Of the 62 prescriptions reported by all ten participants, 33 drugs were taken by older adults-aging with a disability (Group 1) and 29 by older adultsaging into disability (Group 2). Seven OTC medications were taken by Group 1 and five by Group 2. Comparing genders and prescription/OTC medication use showed that females took slightly more drugs than males. The ratio of the 62 prescriptions reported by the ten participants was 34 females: 28 males.

People with disabilities (Group 1) tended to live in a family setting whereas people who had developed disability with aging (Group 2) tended to live alone. Because of the smaller sample size of the groups, differences were more obvious. There seemed to be no differences between gender and living arrangements, age groups and living arrangements, age groups and prescription/OTC medication use. However, there seemed to be a slight difference between prescription medication use and living arrangements. People who lived with a family took more prescription medications than those who lived alone.

Overall, the descriptive statistics did not indicate any obvious differences, possibly due to the small number of participants in each group. An overview of the descriptive statistics is given in Tables 8a and 8b.

Group			1 (aging v	vith a disabi	ility)	Group 2 (aging into disability)				ility)
Gender		Age years	Rx* (n)	OTC** (n)	Living arrang.		Age years	Rx (n)	OTC (n)	Living arrang.
Female	G1S1 G1S2	81.86 65.55	9 6	1 3	spouse spouse	G2S1 G2S2 G2S3	83.11 82.99 93.49	4 11 4	2 1 1	alone daughter alone
Male	G1S3 G1S4 G1S5	80.26 75.97 64.40	6 9 3	1 0 2	spouse alone spouse	G2S4 G2S5	73.38 87.71	4 6	1 0	spouse alone
Total	N=5	73.60	33	7		N=5	84.13	29	5	
Rx* - 1	orescripti	on medi	cation,	OTC**	– over the	counter	medicat	ion		

Table 8a: Descriptive Statistics

T	able	8b:	Descriptive	Statistics
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Gender			Female	es				Male	s	
		Age years	Rx (n)	OTC (n)	Living arrang.		Age years	Rx (n)	OTC (n)	Living arrang.
G1 (aging				······						
with a	G1S1	81.86	9	1	spouse	G1S3	80.26	6	I	spouse
disability)	G1S2	65.55	6	3	spouse	G1S4	75.97	9	0	alone
• /						G1S5	64.40	3	2	spouse
G2 (aging	G2S1	83.11	4	2	alone	G2S4	73.38	4	1	spouse
into	G2S2	82.99	11	1	daughter	G2S5	87.71	6	0	alone
disability)	G2S3	93.49	4	1	alone					
Total	N=5	81.40	34	8		N=5	76.34	28	4	

Section 2

Quantitative:

Quantitative data showed apparent differences, probably due to the small number of participants. However, this is not to suggest that the data is not unimportant. Based on the number of responses in the different categories identified in the framework outlined in Figure 2, it seemed that participants perceived slightly different levels of importance in their 'medication taking' management/usage. Key themes were systematically organized to outline inter-related but distinct factors of higher and lower perceived importance. The results outlined in the following sections were scored on a scale from 1 to 5, from lower importance to higher importance.

5-Priority (towards higher importance)
4- Importance
3- Importance
2- Importance

1- (towards lower importance)

a) Knowledge and experience:

Table 9a: Medication related key factors on how older adults in both groups perceived the importance of their medication

Aging with a (G	a disability)	Aging into disability (G2)		
Female	Male	Female	Male	
5	5	1	5	
5	5	1	5	
	5	1		
4	1	1	1	
3	1	4		
	4	1		
5	5	1	5	
5	5	3	5	
•	5	1		
	Aging with a (G1 Female 5 5 5 4 3 5 5 5	Aging with a disability (G1)FemaleMale5555554131445555555555	Aging with a disability (G1) Aging into (G2 Female Male Female 5 5 1 5 5 1 5 5 1 4 1 1 3 1 4 5 5 1 5 5 1 5 5 1 5 5 1 5 5 1 5 5 1 5 5 1 5 5 1	

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

For individuals who belong to the group aging with a disability (G1) such factors as *information and familiarity with the medications* as well as *fear/or concerns* lead to high importance (100%). There is a different picture in the group of individuals who developed a disability with aging (G2): only 40% of the group considered *information and familiarity with the medications* as factors of high importance and 40% of the group considered *fear/or concerns*

regarding their medications as a high importance factor. About 50% of all interviewees *considered bad/or odd experiences* with their medications as a lower importance factor. Overall 66% participants of aging with a disability group (G1) and 27% - aging into disability group (G2) considered *knowledge and experience* a higher importance factor.

	Male		Female		
Knowledge and Experience					
	Aging with a disability (G1)	Aging into disability (G2)	Aging with a disability (G1)	Aging into disability (G2)	
	5	5	5	1	
Information/Familiarity with the	5	5	5	1	
medication	5			1	
	1	1	4	1	
Bad/odd experiences	1	1	3	4	
	4			1	
	5	5	5	1	
Fears and concerns	5	5	5	3	
	5			1	

Table 9b: Medication related key factors on how older adults (females vs males) perceived the importance of their medication

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

There is a slight gender difference regarding the priority of the importance of key factors such as *information and familiarity with the medications*. All males in the study group (100%) considered the above mentioned key factors as being of high importance whereas only 40% of all females did. In regards to the *fear/or concerns* key factor, 100% of all males and 40% of all females considered this key factor as a high importance factor. About 60% of all males and 40% of all females in the study considered *bad/or odd experiences* with their medications as a lower importance factor. Overall 66% of all males and 27% of all females in this study considered *knowledge and experience* a higher importance factor.

b) Relationship with Health Care Provider:

Relationship with Health Care Provider	Aging with (G	a disability (1)	Aging into disability (G2)	
	Female	Male	Female	Male
	5	5	5	5
Doctor	5	5	5	5
		5	1	
Pharmacist	5	5	5	5
	5	5	5	5
		5	1	

Table 10a: Medication related key factors on how older adults in both groups perceived the importance of their relationship with health care provider

5- Priority (towards higher importance)

- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

Approximately 90% of all subjects in both groups considered the *relationship with health care provider (both doctor and pharmacist)* as a higher importance key factor. *Only 10%* of all subjects in both groups considered the *relationship with health care provider (both doctor and pharmacist)* as a lower importance key factor. Overall 100% participants of aging with a disability group (G1) and 80% - aging into disability group (G2) considered the *relationship with health care provider* a higher importance factor.

Table 10b: Medication related key factors on how older adults (females vs males) perceived the importance of their relationship with health care provider

Relationship with Health Care Provider	Ma	ıle	Female		
	Aging with a disability (G1)	Aging into disability (G2)	Aging with a disability (G1)	Aging into disability (G2)	
	5	5	5	5	
Doctor	5	5	5	5	
	5			1	
	5	5	5	5	
Pharmacist	5	5	5	5	
	5			1	

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

Relationship with health care provider (both with doctor and pharmacist) was considered

as a higher importance key factor by 100% of all male participants. On the other hand, 80% of

all females in a study considered the *relationship with health care provider (both with doctor and pharmacist)* as a higher importance key factor.

c) Drug Management:

Table 11a: Medication related key factors on how older adults in both groups perceived the importance of own activity and assistance with their drug management

Drug management	Aging with a disability (G1)		Aging into disability (G2)	
Di ug management	Female	Male	Female	Male
	5	5	1	5
Own activity	5	5	1	5
		5	1	
·····	1	1	5	1
Family	3	1	5	1
(assistance)		3	5	
	1	1	1	1
Other	4	1	1	1
(assistance)		4	1	

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

All individuals who were aging with a disability (G1) (100%) considered *own activity in drug management* as a higher importance key factor. The majority (70%) of interviewees who

belonged to the group aging into disability (G2) considered the above mentioned key factor as higher importance. About 80% of all subjects in both groups considered *assistance with medications from others* as a lower importance key factor. It was noted that 100% of participants in the group aging into disability (G2) considered *assistance with medications from others* as a lower importance key factor. *Family assistance with medications* was a higher importance key factor for only 30% of all participants and a lower importance key factor for 50% of all participants. Overall 33% of participants in the aging with a disability group (G1) and 33% - aging into disability group (G2) considered *drug management* a higher importance factor.

Table 11b: Medication related key factors on how older adults (females vs males) perceived the importance own activity and assistance with their drug management

	Male		Female		
Drug management	Aging with a disability (G1)	Aging into disability (G2)	Aging with a disability (G1)	Aging into disability (G2)	
	5	5	5	1	
Own activity	5	5	5	1	
	5			1	
	1	1	4	1	
Family	1	1	3	4	
(assistance)	4			1	
	5	5	5	1	
Other	5	5	5	3	
(assistance)	5			1	

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

Own activity in drug management was considered as higher importance key factor by 70% of all participants of both gender groups. On the other hand, *assistance with medication by others* was considered as a lower importance key factor by 80% of all participants of both genders. *Family assistance with medications* was considered as a lower importance key factor by 90% of all males in the group study, and by 30% of all females as a higher importance key factor. Overall 66% of all males and 26% of all females in this study considered *drug management* a higher importance factor.

d) Attitude:

Attitude	Aging with a disability (G1)		Aging into disability (G2)	
Attitude	Female	Male	Female	Male
Attitude regarding medication use	5	4	4	5
	5	4	5	5
		5	4	
	5	5	5	5
Attitude regarding well-being	5	5	4	5
		5	3	

Table 12a: Participant related key factors on how older adults in both groups perceived the importance of their attitude regarding their medications use and well-being

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

In this study, 70% of all participants in both groups considered *attitude* as being a higher importance key factor in relation to medication use and well-being. About 80% of the participants aging with a disability (G1) considered *attitude* as being a higher importance key factor in relation to medication use and well-being. Among participants in the aging into disability group (G2), 60% considered *attitude* as being a higher importance key factor in relation use and well-being.

	M	ale	Female		
Attitude	Aging with a disability (G1)	Aging into disability (G2)	Aging with a disability (G1)	Aging into disability (G2)	
	4	5	5	4	
Attitude regarding	4	5	5	5	
medication use	5			4	
	5	5	5	5	
Attitude regarding	5	5	5	4	
well-being	5			3	

Table 12b: Participant related key factors on how older adults (females vs males) perceived the importance of their attitude regarding their medications use and well-being

5- Priority (towards higher importance)

- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

This study indicated that 60% of all participants (females and males) considered *attitude* a higher importance key factor in relation to medication use and 80% of all participants (females

and males) considered *attitude* a higher importance key factor in relation to well-being. Overall, 80% of all males and 60% of all females in the study considered *attitude* a higher importance key factor in relation to medication use and well-being.

e) Medical condition/or disability:

Table 13a: Participant related key factors on how older adults in both groups perceived the importance of their health issues and disability regarding their medication use

Medical Condition/or disability	Aging with a disability (G1)		Aging into disability (G2)	
	Female	Male	Female	Male
	4	4	3	5
Health Issues	5	5	5	5
		4	3	
	1	5	1	1
Disability	4	2	1	1
		5	3	

5- Priority (towards higher importance)

- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

Among those participants who were aging with a disability (G1), 60% considered *health issues* as a fourth key factor in relation to medication use and well-being. About 60% of individuals in the aging with a disability group (G1) considered disability as being a higher or/fourth importance key factor in relation to medication use and well-being. Ninety percent of those who were aging into disability (G2) considered *disability* as being a lower importance key

factor. Overall, 40% of participants in the aging with a disability group (G1) and 30% - aging into disability group (G2) considered *medical condition/or disability* a higher importance factor in relation to their medication use and well-being.

Table13b: Participant related key factors on how older adults (females vs males) perceived the importance of their health issues and disability regarding their medication use

	Ma	ıle	Female		
Medical Condition/or disability	Aging with a disability (G1)	Aging into disability (G2)	Aging with a disability (G1)	Aging into disability (G2)	
	4	5	4	3	
Health Issues	5	5	5	5	
	4			3	
	5	1	1	1	
Disability	2	1	4	1	
	5			3	

- 5- Priority (towards higher importance)
- 4- Importance
- 3- Importance
- 2- Importance
- 1- (towards lower importance)

Sixty percent of all females considered *disability* as a lower importance key factor in relation to medication use, whereas only 20% of all males did. In addition, 60% of all males considered *health issues* a higher importance key factor, in comparison to only 20% of females. Overall, 40% of all males and 20% of all females in this study considered *medical condition/or disability* a higher importance factor.

Section 3

Qualitative:

Qualitative data is not limited by the sample size and tends to be comprehensive (Cresswell, 1998). While answering the interview questions, participants had the opportunity to provide insightful responses. The participants' responses were on some points very different, while some had commonalities. The final thematic analysis of the study transcripts identified five themes: (1) knowledge and experience, (2) relationship with healthcare provider, (3) drug management, (4) attitude towards to medications use, and (5) perceived impact of medical condition/or disability on medication use.




The thematic framework developed from those themes *(see Figure 2)* is presented with a more in-depth explanation of the each theme, and with both the researcher interpretation and verbatim examples of participants' comments.

a) <u>Knowledge and experience:</u>

Knowledge and experience have an influence on the perception of use of medication. Several subtopics emerged within this theme, including acceptance and necessity of medications, medication fears and concerns. Participants offered rich in-depth narratives of their experiences with medication. In general, there was some knowledge about the names, dosages and uses of their medications. Medication was an important aspect of the participants' lives and they took advantage of the interviews to share their experiences and reflect upon these in an open way. Knowledge and purposes were influenced by external factors, such as healthcare, family caregivers and peers. Participants associated importance to their medications according to their doctors' medical advice and emphasis on health effects.

Older adults who received family assistance in managing their medications often lacked an understanding of some of their own treatments and some of them felt fully dependent on caregivers. Finally, there was a tendency for individuals to compare their knowledge and importance of responsibility for their own actions regarding their medication management with those of their peers. "*Really, some people are not able to think about it (medication use) or pay attention. I know people, who have a prescription for something and you ask what are you taking? I don't know. They don't think. Whether (they have) no interest, or they are not able to; they have that kind of personality. I feel it's very important and probably will be always, to know* exactly what I am taking and what its strength is. Also if someone gives you a wrong pill and you don't know, you can be in trouble." (G1S2, female-65)

Participants mentioned three important beliefs about their medications: taking medication is not optional (you have to take them if you want to live or feel better), it is important to ask questions about your medications; and medications help provide control over their own health. For the majority of older adults, taking their medications appears to be a necessity, not an optional choice in improving their quality of life:

"If it wasn't for the Humira shot every day, I think it would probably be hard to be able to get off the bed. It was the most wonderful thing. Medications are positive in my life, very positive. It has made me much more independent, being a lot less in pain. I pretty much do everything I want to do." (G1S2, female-65)

"Is my life better because of medications? I think if I wouldn't take those pills I would feel worse and would be really sick. I think they help me more than do harm to me. I feel if I wouldn't take those pills I would feel much worse and maybe wouldn't be able to live in my house. I would be in a hospital all the time. But I still think I take too many pills." (G2S2, female-83)

The way in which medications affected individuals' control over their health also influenced their expectations of their medications. Some interviewees noted that medications gave them an opportunity to gain control over their health; whereas others thought that because of taking medications, they have no control over their health. Some individuals described having to adjust their lives to their medications because they were taking a lot of medications or had serious health problems. Others had incorporated taking medications into their lives so they could still do everything they wanted to do: *"They (medications) give me a chance to live. True.* I would not survive without them. I have some independence. I still drive my car. I still can do some daily activities. "(G1S5, male-65)

Medications were considered more important if they were prescribed to relieve symptoms, or maintain a condition. Those participants who were diagnosed with their medical conditions earlier in life (before age 65) and started to take medications at that time, had a perception of higher importance in relation to knowledge and purpose of medication use. Lower importance of medication was assigned because of lack of knowledge about medications and lack of interest in them. Thus, some people who had started to take medications when their health declined due to the natural aging process, tended to think about medications as a lower importance factor. *"I can show you the pills but I have no idea do they help me or make it worse. Because I never took medications till I came here (senior's apartment). I don't know, do they help me or not. I have no idea, but I am still taking them.*"(G2S3, female-94)

"I have never thought about this before and I don't think now. I don't take many medications (4). I have never had any doubts why I take those pills, or any questions like do I need to take them. No, I have never asked myself those questions. I don't have an interest about medications at all. I don't want to know much about it. Whatever I need to know my daughter will tell me."(G2S1, female-82) Importance ratings were generally lower when older adults could no longer remember the significance of their longstanding therapy, could not recall a discussion about their therapies with their doctors or were passive about making medical decisions.

Participants spoke about both positive and negative experiences with medications. Those who had positive experiences described how the medications had helped them and this was the reason why they continue taking them. Negative experiences sometimes caused older adults to be aware of side effects of their drugs. Those who had side effects that they considered severe or serious often thought they had to deal with them on their own, as they were not getting enough support or understanding from their health care providers. "Only one time I had a bad experience. I used to have cystitis and they gave me sulpha. During the month they were giving me sulpha, I kept passing out. I phoned to the pharmacy at the university, I found out I am allergic to sulpha. I am also allergic to a few other things, one of them was Demerol. After my heart surgery they wanted to start me on Demerol but I told a nurse I am allergic to Demerol. She didn't believe it. She didn't listen to me. I had a bad reaction after I was injected." (G1S1, female-82) Those bad or odd experiences helped them to realize what might happen to them in the future if they took the same or new medications. Some of the participants indicated that taking medications can be a balance of benefits and risk: "Of course medications have some side effects but it is still worth it to take them, because they help. I had some problems with the side effects of the different dosages of Mirapex. I told my doctor that something was wrong with me. Then he switched to higher dose of Sinemet instead. It is very important to listen to your *patient*."(G1S5, male-65)

One 84 year old female discussed an unexpected bad experience she went through because she was not being properly informed about the importance to use her new medication for her severe heart condition. As a result she was hospitalized for one month. Sometimes negative adverse effects occurred because the patients had too much information to process when they were ill.

Some of the participants talked about how their medications affected symptoms or signs of their medical conditions, their physical and emotional state. "I have trouble with some medication-Mirapex. First time when I started on Mirapex it was very difficult to accommodate

the medication and my body response for the three months. It took me so long. Changes with medications change my emotions. I started to cry. That is why I don't go out much. Now it seems stable. I think I lost some weight. I cannot write nicely because my hands move a lot. I think it's happened because of the medications."(G1S5, male-65) For some elderly adults, taking medications was seen as a way to cope with their medical conditions. "O, ya. O, ya. Medication for restless leg syndrome-I don't know what I would do without it. When it starts, my muscles...it just feels like my legs are like rock."(G1S3, male-80)

For most of participants, medications were seen as a way to help manage life and conduct daily activities. Some individuals also noted that taking their medications led to an improvement in health that also allowed them to do things that otherwise they might not have been able to do. Some participants were able to express specifically what they expected their medications to do. They were looking for a reasonable outcome from their drugs (eg, reduce of pain in their knees, reduce swelling of the feet). "*I know I have high blood pressure so I have to take some pills for it. The doctor wanted to give me water pills because my right foot is swollen. But it bothers me because I have to go to the washroom often.*" (G2S1, female-82)

There were some concerns about the cost of medications and this revealed the fact that this is an important issue for many older adults. If individuals cannot afford to pay for their medications it will lead to poor adherence. "*I do order medications myself. I have to pay for them. It's very expensive. You can see the prices on the labels. It's about 400 dollars a month; it's a lot of money. Pharmacare helps.*" (G1S1, female-82)

Polypharmacy or feeling to be overmedicated was an additional concern raised by only one participant during the discussion about her medications use. "*I think I am taking too many medications (11). My cholesterol is better now. Maybe the pills work for me so I guess I have* to take them. I don't have specific concerns. I still wonder why I take so many pills. But I listen to my doctor."(G2S2, female-83) Nine participants indicated that taking multiple medications does not bother them or posed no particular burden to their lives, and seemed to indicate that adherence was not a particular difficult issue. On question about feeling to be overmedicated, one response was: "Not at all, because my doctor knows what to prescribe, he knows what I need and I listen to him. That's why I am on so many medications (9). I couldn't live without medication. I think it's fine."(G1S4, male-76) Overall, beliefs about taking medications seemed to reflect a feeling that taking too many medications is fine. One female, who was diagnosed with diabetes a long time ago, on the above mentioned question about feeling to be overmedicated, answered: "Absolutely not. My doctor would like me to go on insulin and I don't want to. That's why I am on so many medications (9). I couldn't be without medications. I feel it's okay."(G1S1, female-82).

All their narratives contributed to the framework for the 'knowledge and experience' theme.

b) Relationship with health care provider:

The relationship with the healthcare provider nurtures their perceptions regarding use of medication. In light of the participants' responses, there appear to be two agents in the fields of health care providers' assistance with medications management: doctors and pharmacists. Doctors are gatekeepers for prescription drugs and they also have considerable influence over OTC drugs. Their power is based on legislation and education. Physicians' credentials and years of practice further strengthened the patients' view of the use of medication. They also have the strongest public voice and enjoy the greatest social esteem. The older adults' responses indicated

that the importance of taking their medications depends on a relationship of trust with their doctors. It was found that having a good relationship with a health care provider was an important indicator of whether participants would discuss their concerns or needs about medication with their doctors or pharmacists. Most of the participants were satisfied with their physicians and quality of communication with them. "My doctor is very careful and is a very nice man. He listens and answers to any questions. He is a nice fellow. "(G1S1, female-82) "My doctor is very receptive and very understanding. For example with pramipexole, someday I take five tablets someday I take four tablets, it depends on how I feel. I discussed this with my doctor and he said go ahead and do that, that it's called self-administration. He said you know your body better, how it reacts to this medications. I trust my doctor and he knows what is required."(G1S3, male-80) A positive relationship and trust in their doctors were seen in this response: "My old doctor was careful. When I had a blood test done-he always would phone me back to explain about the dose of warfarin to be increased. I've never asked about medications. I trust my doctor because he knows what to prescribe. This doctor changed his practice, he moved to another clinic, very far away. Now I go to see another one who is also good and *understanding*."(G2S5, male-88)

Some older adults were talking about their relationship with health professionals as disconnected, with a lack of understanding and attention to relationship. One example was the complaint that their physicians did not spend enough time with them, did not communicate well with them, did not listen to them. They expected to be treated with understanding. "*I was diagnosed with Parkinson's disease ten years ago. It was really hard in the beginning. I wish I had some literature to help me to understand what's going on with me, what I can expect, what I can do to help myself. I had one problem then, I wasn't happy with my doctor (specialist). It*

seemed he didn't want to understand me, didn't have time to explain the questions I had. He said one day, that if I didn't like to come here (to see him) I could go to see the other doctor. I made the decision to change the specialist and asked my family doctor to help me to find another one. Now I go to see another doctor. This doctor is very nice and very helpful. I know he has only about 15 minutes for me but his attitude is different." (G1S5, male-65)

The majority of participants mentioned that they asked their physicians questions about medications if they had any. Only one respondent voiced the belief that their physician did not want to discuss medication issues with them: "No, he doesn't care much. He just comes and looks at you. My feet hurt, he will say: "What do you expect? Do you want to run a tractor?" He doesn't care. He thinks I am old. "You are 90-years old, why should I play with you? I have kids waiting for an appointment." (G2S3, female-94) The doctor's negative attitude gave the impression of negligence and carelessness towards his patient due to her being very old.

One participant who expressed his thoughts about the short duration of appointments with a doctor blamed it on the health care system: "*The availability and kind the medicine we have her, in the province and nationally. Doctors are on a time schedule. The patients are not paying them, the state does. For these doctors to be professional is very difficult because the state is making them keep the visit time maybe to 15 minutes. Many doctors have a sign on their counter that they may only see you for one thing that is wrong with you. There is a reason they have that...they feel the pressure of not being able to help you enough. That leaves the gap. And that gap is filled by the pharmacist if the pharmacist is open and willing to talk to them. I believe a pharmacist become accessible.*"(G2S4, male-73)

Doctors carry greater authority than pharmacists, and advice from pharmacy staff does not have the same status as advice by medical doctors. However, the participants' point of view implied that assistance from pharmacists played a big role in their drug management. "I order and buy my medications myself. I go to one pharmacy. I order medications and wait 15 minutes or so to pick them up. I always have questions for the pharmacist. I know the owner of this pharmacy and she knows me. She is a nice lady and very helpful. Sometimes she gives me good medical advice. For example, she told me about meclizine. This medication doesn't have any medical values, it doesn't treat, but rather, it just relieves the symptoms. This is why I don't take meclizine regularly."(G2S5, male-88) Another positive response in favour of pharmacists was: "I go to Safeway pharmacy. They do bubble packs and deliver them. Safeway is very helpful. I know my pharmacist. I have a very good relationship with the pharmacy."(G1S1, female-82)

All these narratives contributed to the framework for the 'relationship with health care provider' theme.

c) Drug management:

Drug management is facilitated by the perception of use of medication. The majority of the participants reported they were keen to self-manage their medications. They provided detailed accounts of the numbers of tablets they took and when and how they had to be taken. Seven participants did order and picked up their prescriptions from the pharmacy by themselves (or used delivery service) and, for three of them, family caregivers did. Seven participants used a compliance packaging for their drugs to manage their medication regimes. Two people used a pharmacy service for making compliance packaging, two did them by themselves, and, for three individuals, their family caregivers arranged them on a weekly basis. This enabled them to take their medications at the same time and not to miss any doses. *"I went on compliance packaging*

for myself. Then I have no questions whether I took them or not. I use compliance packaging and I think it is excellent. So I am very happy about this."(G2S4, male-73)

One female, who was diagnosed with glaucoma, used big prescription containers which are easy to open and have names of each day of the week written in black on top. This helps to manage her medications regime despite her impaired vision. An 80 year old male participant, had developed a chart where he made a record of each dose of his medication taken. "*I will show you my notebook. I write down the time, date when I take medications: 9:00 am, 1:00 pm, 6:00 pm, 9:00 pm; March 12,..13,...and the name of the pill. After each time I take a pill I make a record here. I found this method very effective for me. If I don't make any record it means I missed taking this pill. It's working for me.*"(G2S5, male-88)

Three participants indicated they rely on family caregivers to help them manage their medications regimes. "My daughter lives with me and she helps me with my medications. She goes to "Costco Pharmacy". There is a good service. The pharmacist always explains how to take medications to my daughter and then she tells me. I am very happy with my pharmacy. So far I have enough help. My daughter helps me a lot. I notice I don't even think much about my pills. I think because I am fully dependent on my daughter and I trust her. Maybe if I have to order my medications from the Pharmacy myself and have to put them in a weekly box I would think more and would worry more about those medications. It would be hard."(G2S2, female-83) Those individuals who received family assistance in managing their medications often lacked an understanding of some of their own treatments and as a result they had no interest in knowing about it. "I don't have an interest about medications at all. I don't want to know much about it. Whatever I need to know my daughter will tell me. I don't feel frustrated because I trust my doctor, my pharmacist, and my daughter. I fully depend on them. I know I am in good hands."(G2S2, female-83)

Respondents in this study identified a need for support and advice in medications management for others (older adults), however were uncertain where to seek this help. "*I think maybe a doctor could say something more to the patient. I think it depends more from a doctor*." (G2S2, female-83)

Finally, assistance with medications from others resources (such as an informative educational program offered by medical clinic or association, and meetings with a support group) was reported by two participants, as important factors of their medication management on some level. "*My doctor said: "You know more about the disease than me"*. *His nurse gives me a lot of information about this disease, about medications I have to take. She advised me to join a support group. The support group is very informative and useful. People come there to talk about common problems and share the personal experiences and the knowledge. The nurse from the clinic told me about the educational lectures for Parkinson's disease (usually they have them at the Wellness Institute). I also receive informational letters from the Parkinson's Association."(G1S5, male-65)*

All these narratives contributed to the framework for the 'drug management' theme.

d) Attitude towards medication use:

Attitude determines older adults' perceptions regarding the use of medications. Although a number of factors play a role in the patient's decision as to whether or not to take the medication, attitudes and beliefs about health and illness have been consistently identified as the major factors in such decisions. Despite the fact some individuals were not aware of the significance of their longstanding medications, others presumed high importance because they had taken the medications for many years. Participants who thought their health problems were not as severe generally rated their medications as less important.

During the interviews, 75% of all participants showed positive attitudes with their responses. One response to a question of whether medications improved his/or her life was:"*I believe those pills help me. I feel much better now.*" (G1S1, female-82); 14% had a neutral attitude: "*I think so. This is why a doctor prescribes them.*"(G2S5, male-88); and only 11% had negative attitude: "*I have no idea. I don't think so.*"(G2S3, female-94) It was found that majority of respondents offered positive attitudes toward their medications regimes. "Medications are positive in my life, very positive. It has made me much more independent, being a lot less in pain. I pretty much do everything I want to do. "(G1S2, female-65)

When questions about their medications and their affect on their health and well-being were posed, those respondents who were 80 and older had a tendency to blame any symptoms they felt on their age "In general I feel fine. I still walk, and do some work around the house. I feel more tired. I do not feel as disabled or having some restriction in my daily living. It's probably with age. I feel more tired and weak. I understand that aging is a natural process - I cannot expect myself to feel healthier and better the next day. I cannot do as much work and activities as I did when I was younger. It's true. To be old is not fun. I also don't have a desire to do the work as I used to do before. I feel like I need more rest." (G2S2, female-83)

Similarly, the attitudes of those who had been diagnosed with some medical conditions before age 65 slightly differed from those who developed a medical problem after the age of 65. Participants who had been coping with their illness or impairment for a long time ago (before age 65) had a more positive attitude and the ability to balance their beliefs about their medication and the impact of the illness. For them, once a treatment was accepted, it became part of life, was built into the daily routine and was no longer an issue. "*I'd be totally dead without medications, It's been a long-long time. I find a pharmacy is very-very helpful. How do I feel generally? I have to keep my spirits up. If I allow myself, I can go down and become depressed. I have to keep it up with my friends. I go out time to time."*(G1S1, female-82)

In contrast to the negative attitude offered by one person, nine respondents acknowledged the importance of medications and indicated that their medication regimen did not bother them. "I don't feel over medicated? Not at all, because my doctor knows what to prescribe, he knows what I need and I listen to him. That's why I am on so many medications. I couldn't live without medications. I think it's fine."(G1S4, male-76) They also indicated that the medications were available to take care of their problems. These respondents felt that the medications they were taking were more positive than negative: "Of course medications have some side effects but it still worth it to take them, because they help. When I was taking medications the first time, I had the feelings that I want to fight to be alive. They give me chance to live. True. I would not survive without them. I have some independence. I still drive my car. I still can do some daily activities."(G1S5, male-65)

Two groups of users of medications were identified in this study sample. Passive users adhere to their prescribed medication and, as a rule, did not question the need for medication, whereas active users fully engaged in their medicine intake. Some participants had very clear opinions about the value of attitude and being actively engaged in shared medication-specific decision making. *"I think the attitude is a key. You have to be positive and not afraid to ask any*

questions of your doctor, a pharmacist, or anybody who has to deal with your medications. Your health is in your hands. You have to take care of yourself. You should be an active participant when it comes to making decisions in relation to your health and treatment."(G1S4, male-76)

All these narratives contributed to the framework for the 'attitude' theme.

e) Perceived impact of medical condition/or disability on medication use:

To understand whether the disability/or illness has any impact on drug management, the older adults were asked the open-ended questions: "How do you feel generally?", "Do you feel limited in your daily living activities by having an impairment?"

"I am disabled to the point where I can't hold a job. I can't do that. I am restricted in some of the activities. With the help of the medications and all the helpful aids they have for people with arthritis I do great, so long as I am concerned. I can pretty much enjoy a full life. "(G1S2, female-65) "Generally I feel not bad. For different people it's probably different. I still read a lot about Parkinson' disease, and try to learn about this condition. It should be a balance of all factors: walking, diet, medication. You have to communicate with your doctor, nurse, and pharmacist. Communication is important."(G1S5, male-65) Balancing the concerns of taking medication and the concerns of what might happen without medication was part and parcel of everyday life for those living with illness or impairment for many years. To a question about how she felt when she began to take her first medication, one female responded: "I think personally, I was happy to have something that would make my life more enjoyable, a little easier to do things. So my way of thinking is, have something that improves your quality of life and makes you more independent rather than being in pain and not being able to go do things." (G1S2, female-65)

This study revealed that one aspect of medication taking behavior relates to the acceptance of an illness or impairment. Participants' responses were a reflection of individuals' perceptions of their illness and the role of medication in its management. Just as the acceptance of medication develops over time, concerns over the consequences of living with their illness could also alter with experience, in particular with the severity and frequency of ongoing symptoms. For many participants, the fear of the impact of actual symptoms is a fine balance with how necessary they perceive their medication to be. "*I feel if I wouldn't take those pills I would feel much worse and maybe wouldn't be able to live at my house. I would be in a hospital all the time. I think they help me.*"(G2S2, female-83)

Some participants described having to adapt their lives to their medications, particularly if they were taking a lot of medications or had many health problems. Others had incorporated taking medication into their lives so they could still do everything they wanted to do: "Generally I feel fine. There is a message here for all of us who are old and suffer from different medical conditions, and that we can still do many of the things we used to do. We can still enjoy things we used to do. By adjusting the ways we do things, we can continue doing almost anything we wish to. Slow down, pace yourself, take your meds, keep positive attitude, and you could be amazed what it will do for you." (G1S4, male-76)

Some participants commented about how taking medications was seen as a way to cope with their illness or impairment. This highlighted the emotional toll some medical conditions take on older adults and the value that was seen in taking their prescribed medications. All their narratives contributed to the framework for the *medical condition/or disability* theme.

Section 4

Comparison of similarities and differences in the qualitative and quantitative data:

Results described in this section are based on the Final Thematic Framework *(see Figure 2)* with respect to the four groups (older adults 'aging with a disability' (G1) versus those 'aging into disability' (G2) and between females versus males). The exploratory results are outlined in Table 14. These results showed that there was a slight difference in responses between the male and female groups in all five themes. For example, the group of male participants responded on average 66% more often on questions relating to *'knowledge and experience'*. The comparison between groups, 'aging with disability' (G1) and 'aging into disability' (G2), showed some difference in four themes (*'knowledge and experience', 'relationship with health care provider', 'attitude', and 'medical condition/or disability'*). For instance, the group aging with disability (G1) seemed on average, higher on all questions except on questions relating to drug management. Table 14 stresses the strength of the data, since it was possible to provide examples for each theme from each participant for both analyses.

As evidenced by	Type of Data	Gender		Groups		
		Male	Female	Aging with a disability	Aging into disability	Comparison
Knowledge and Experience	Quantitative	66%	27%	66%	27%	M>F, G1>G2
	Qualitative	"I know my medications. I have taken them for many years"(G2S5M)	"I have no idea do medications help me"(G2S3F)	"I know well what I take and why I take them"(G1S3M)	"My greatest concern is effectiveness" (G2S4M)	
Relationship with health care provider	Quantitative	100%	80%	100%	80%	M>F, G1>G2
	Qualitative	"I trust my doctor"(G1S3M)	"I trust my doctor. He is very nice" (G2S1F)	"My doctor is very nice and very helpful"(G1S5M)	"I always have questions for the pharmacist" (G2S5M)	
Drug Management	Quantitative	66%	26%	33%	33%	M>F, G1=G2
	Qualitative	"I order and buy my medications myself"(G2S5M)	"My daughter helps me with medications" (G2S2F)	"I do phone the pharmacy to order my meds and they deliver"(G1S4M)	"Whatever I need to know my daughter will tell me" (G2S2F)	
Attitude	Quantitative	80%	60%	80%	60%	M>F, G1>G2
	Qualitative	"I couldn't live without medication"(G1S 4M)	"I have to keep my spirits up" (G1S1F)	"Medications are positive in my life"(G1S2F)	"It's your health"(G2S3F)	
Medical condition/or disability	Quantitative	50%	20%	40%	30%	M>F, G1>G2
	Qualitative	"They (medication) gave me chance to live. I have some independence"(G 1S5M)	"I can pretty much enjoy a full life" (G1S2F)	"I'd be totally dead without medication" (G1S1F)	"I feel good if I don't count pain in my knee"(G2S1F)	

Table 14: Comparison of similarities and differences of the results between groups

DISCUSSION

Qualitative research can illuminate complex psychological issues. In qualitative inquiry, the aim is to adequately answer the question in the area under investigation or present a new theoretical basis for further research (Cresswell, 1998). This research attempted to understand the broad range of perspectives on the use of medication by older adults. It also was meant to analyze these perspectives across two specific groups those who are aging with disability (G1) and those who are aging into disability (G2). This exploratory study examined the practices and experiences with drug usage of ten individuals, age sixty five and over, who either developed a disability or impairment before the age of sixty five or who were aging into a disability.

The five themes, knowledge and experience, relationship with healthcare provider, drug management, attitude and medical condition/or disability are grounded in their responses. The thematic framework developed in this study demonstrated that older adult's perceptions on medication use linked to the above mentioned five themes through activities that helped them confirm or modify their perceptions. The data of this study explored the levels of how older adults perceive different levels of importance among their medication related medication.

Factors that impact older adults' knowledge and experiences about medications were identified from their responses on interview questions. One of these factors was duration or how long they have been prescribed the medications. Individuals who had begun to take medications when they were diagnosed with their illness before age 65 year (G1) understood their medication very well. They recalled names of medications, as well as their purpose. They were concerned about effectiveness or adverse/side effects. This group often remembered the daily dosage of medications they took. This was supported by that fact that taking medications for a long time not only familiarizes the participants, but they also become more interested in medications and more responsible for themselves. When individuals are diagnosed with a medical condition, it requires them to think more about medications. They often ask health professionals many questions and do research about their medications from different sources. They are interested in trying new therapies, with the hope this will make their lives easier, and will take pain away or alleviate difficult symptoms.

Participants who started taking medications in the later stage of their lives (after age 65 years) tended to have much less knowledge about their medications. At times, during interviews it was difficult for them to remember drug names and dosage details. It also seemed that to be difficult for them to manage their own medication regimes. Because of lack of knowledge, they lost interest in knowing about medications. Previous research shows that often, they express a reluctance to accept and understand the purpose of the medications they are prescribed (Jennings-Sanders, 2001). Some participants thought they lacked information about their medication. These older adults likely made risk-benefit assessments, without full knowledge of the medications' known risk-benefit profile. This result was supported by studies which demonstrated that patients needed more information about medications they took (Berry, 1997; Couldridge, 2001). These older adults felt more comfortable if they had help with medication management from their caregivers (children, spouses). This makes an older adult more dependent on someone. It is also noted that knowledge about medications is sometimes affected by the education level of the person regardless of the age. One of the participants, an 88 year old male, who lives alone and had university degree, was knowledgeable about the medications he took. Overall the older adults in the aging with disability (G1) group appeared to be more

knowledgeable and familiar with their medications. They also had more experiences with questions how to deal with an adverse effect.

During the analysis of the theme '*drug management*', it was found that seven participants do this task well on their own, while three of them fully depend on help from caregivers. Those who showed the latter behavior belonged to group (G2), aging into disability. Responses from participants in group (G2), especially those who got help from their daughters demonstrated 'daughter-mother bonding.' The bonding, in these cases, interfered with the sense of independence and responsibility for their own drug management; because of 'mother-daughter' bonding these individuals depended on external help for their medication taking. One of the participants, an 83 year old female, indicated that if it would not be for her daughter's help she would think more about the medications she took and would feel more responsible and, as a result, would be concerned more about her medications. The participants from the other group 'disability with aging' (G1) were very independent and responsible for their own medication taking regimes. One participant, a 65 year old male, occasionally used help from other people such as his doctor's nurse, or from support group members.

Better communication between participants and health care providers could help participants be more engaged in monitoring their progress on therapy, be able to identify medication-induced adverse effects more effectively, feel more fully informed about the therapy they are receiving, and better understand why medications are prescribed (especially for medications to treat medical condition that have no symptoms, such as hypertension or hyperlipidemia). When older adults asked questions about the medications they took, it helped physicians and pharmacists understand their concerns and thus what needed to be explained. Britten and colleagues (2003) identified the need for doctor-patient communication about medications and the need for a conscious recognition of the needs that each brings to medication prescribing and use. Most participants indicated they spoke with their doctors about their medications and were satisfied with their communication. Only one participant mentioned that communication with her doctor was not a positive experience, and that she perceived the reason to be her age (94 years). The way her doctor talked to her and treated her created a negative effect of this participant's belief about the importance of her medication. Therefore, this 94 year old female felt excluded and useless because her doctor said she was "too old."

Piette et al.(2004) showed that the reason for not discussing issues with their doctors included patient embarrassment, not thinking the topic was important enough, lack of trust and lack of time during the clinical encounter. One of the common reason why older adults were not asking questions about their medications was lack of time spent with their doctors. Miscommunication is a big issue affecting the quality of older adult- health care professional communication (Britten, 2002). One example of this was found in this study: one participant said she told her nurse that she had an allergy to some medications and the nurse did not listen to her. As the result, this participant was given medication that cause adverse effect. It is acknowledged that older adults need to be treated as a special group with more attention provided so that they not only understand the need for medications, but also the role medications play in the management of their condition (Butler et al., 2002). This study showed that for all older adults, regardless of age, '*relationship with health care provider* ' based on trust and understanding, nurtures older adults' positive perceptions of use of medication.

This study has been devoted to exploring attitudes of older adults towards medication use and well-being. The majority of the participants reported that they were feeling well, despite the health problems that they may have. Older adults who stay involved with family and friends described themselves as happier than those who lack these connections. Individuals with good support networks are less affected by negative emotions, and are more likely to do things that are good for their health. Everyone starts to face more challenges as they get older. Some people have more trouble than others, but many older adults with disability still enjoy satisfying lives. As this study showed, this is possible by recognizing limitations and making some lifestyle changes. The voice of participants of this study tells us that keeping a good attitude and being in charge of one's own health are both helpful when it comes to well being and drug management.

Positive attitudes to drugs seemed to be related when it was linked to the belief that the medication helps. A good example was the medications that were taken to alleviate pain or bothersome symptoms. As well, good relationships with health care providers help older adults develop positive attitudes towards the use of medication. On the other hand, when an individual was lacking good communication with his/or her doctor, the result would be a negative attitude. In this study, it was found that the majority of older adults had a positive attitude towards managing their own medication and they were often self-managing.

This study also underlines the importance of medications for older adults in maintaining their daily living on a reasonable level. In addition, this study shows how older adults' relationships with health care professionals can influence the way in which they manage their medication and, ultimately, their medical condition or disability. The link between acceptance of medical conditions and medication use has also been described in qualitative research (Dowell, 1997; Adams, 1997). Narratives from this study suggest that the way older adults use their medication changes over time and with experience of their illness or disability. Medication use was central to the management of their multiple symptoms and disabilities. When illness specific medications are necessary to control symptoms that are significantly impacting on quality of life, more general anti-medication beliefs or doubts can be compromised. Once a medication was accepted, it became a part of life, was built into the daily routine and was no longer an issue. This study also showed that older adults who develop a medical condition or disability in a later stage of their life often misunderstand why their health is deteriorating and they blame the aging process. However, the effect of an illness changes their quality of lives.

The theoretical model developed in this study identifies the importance of both individuals' perceptions of use of medication and individuals' attitudes. Simply stated, this means that there is a direct relationship between older adults experiences with drug management, interpretation of the meaning of those experiences and older adults self reflection that defined by attitude. An anticipated finding in this study was discovering the extent to which participants acted with positive attitude, thus this model is presented as positive. However, this model predicts that the attitude of older adults can have an influence on their perceptions of use of medication. For example, often an older adult with negative attitudes tends to be noncompliant and have low self-esteem. This individual has doubts why he or she must take particular prescribed medications. The lack of knowledge and understanding of the role of medication in individual's life can lead to a negative attitude. The negative attitude along with negative experiences can shape negative perceptions of use of medication. When an older adult with this negative attitude sees a doctor, this doctor can change the perception of use of medication of his patient. This change can be possible by explaining their medical condition, the purpose and importance of prescribed medication in plain language, by showing attention to older adult needs and concerns in relation to their drug management. Better communication between the older adult patient and the health care provider could help this patient be more fully engaged in drug management and understand why medications are prescribed. Overall, those actions could lead to a change in an individual's attitude from negative to positive, and thus change the perception of the use of medication which would result in improved compliance and well-being of the older adult patient.





In summary, this study found that older adults' expectations of their medications are grounded in the reality of their experiences, attitudes, beliefs and social or health care situations. During the analysis of the theme '*drug management*', it was found that some participants do well

on this task on their own, while some of them fully depend on help from caregivers. Those who showed this behavior belonged to group (G2), aging into disability. This study showed that for all older adults, regardless of age, '*relationship with health care provider*' based on trust and understanding, and better communication between them could help participants become more engaged in monitoring their treatment. Positive attitudes to drugs seemed to be related when it was linked to belief that the medication helped. In this study, it was found that the majority of older adults had a positive attitude towards managing their own medication and they were often self-managing. This study also showed that older adults who developed a medical condition or disability in a later stage of their life, often misunderstood why their health was deteriorating and they blame the aging process.

CONCLUSIONS

The goal of this study was to explore older adults' attitudes and practices with regards to their medication use. A range of factors, most notably knowledge and experience, relationship with health care provider and own attitudes, influenced older adults' perceptions of their use of medications. Results of this research provides preliminary evidence that older adults assign different levels of importance to all fives themes in the framework.

In particular, this study suggests that the perception of use of medication by older adults is determined by their attitude as defined by personality. Because of different types of personality two types of medication users emerged: active users who take their medication because of their decision, and passive users who take their medication because they were told by doctor or caregiver (Dowell & Hudson, 1997). All active users of medication in this study have positive attitudes. These individuals tend to be more knowledgeable about the medication they take, and therefore they are more compliant and independent in a drug management. Attitudes of passive users are mixed. Passive users take their medications with lack of knowledge and lack of understanding of purpose of the medication in their lives. Those individuals dependent on others and have tendency to be non-compliant.

This study also suggest that older adults' self-reflection on their own experiences of drug management indicates that knowledge and experiences about medical condition and medication along with positive relationship with the doctor produce the motivation for using medications. The results of the study may provide insights to inform health professionals about the development and implementation of better medication regimes and education of older adults in order to understand their needs in relation to the use of medication. As a result of this, older

adults could be provided with personal written instructions along with a prescription by their doctor. Also it suggests that a doctor should spend more time with a patient to make sure that this patient understands their use of medication (especially regarding a new medication). The doctor should communicate with an older adult patient in simple language so a patient would feel confident and comfortable that he or she understands the conversation. This study identifies that one of the needs of older adults with respect to medication use is that the doctor must listen to them. When a doctor listens to older adult patients and pays attention to their concerns it seems to results in a better compliance and improved well-being of older adult patients. They state that they feel better about themselves. One "good" visit with a doctor can eliminate many unnecessary subsequent visits. This research suggests that older adults should be treated with understanding and that one's age should not make any difference.

Results of the study may have impact on policy decision-making. One example is implementing a policy regarding medication use by older adults who live in a community. Health care providers should ask if there is a support and assistance with drug management when prescribing medications to an older adult.

The most important conclusion to be drawn from this study is that older adults who developed a medical condition/or disability before the age of 65 years, though seriously challenged by their illnesses, are more competent in medication management/usage than those who developed a medical condition or disability after age 65 years (Benson & Britten, 2002). This study suggests that the process of accepting a medication as part of the treatment links to accepting their medical condition/or disability (Dowell & Hudson, 1997). Older adults with early onset disabilities or medical conditions are more motivated to use their medications due to the early onset and the knowledge of their illnesses or disabilities. In support of this statement a good example emerged: one male participant with multiple sclerosis, physically challenged, was managing his medication and was also helping his wife with Alzheimer's disease in medication management.

The theoretical model developed in this study, unknown at the onset, is based on the interviews of people who had positive attitudes. This positive attitude influences the predictability of their perceptions. The model effectively predicts that non-compliant individuals can become compliant if they develop a positive relationship with a health care provider, gain more knowledge about medication, have assistance with drug management, have a positive attitude, and understand and accept their medical condition/or disability. This model shows how an individual can change from a passive user of medication, to an active one. This is possible by developing a positive relationship with their health care provider, by changing to positive attitude, by learning more about medications, by improving drug management and by accepting their medical condition/or disability. Finally, by using this model health care professionals can help facilitate compliance of an older adult living alone. This can be achieved with a positive relationship with health care provider, with enhanced knowledge and experience, with positive attitude, with proper drug management (own activity or with assistance) and accepting medical condition or disability. Therefore, this study suggests that is of value to address the concerns and needs of older adults in relation to the use of medication from their own perspectives and use them in improving the quality of medication use.

Study Limitations:

All participants volunteered for this study and, therefore, may have been more knowledgeable than the typical older adult with respect to the topics discussed. It cannot be said that dominant factors that emerged here can be generalized to different age groups or geographical locations. However, the value of this qualitative data is the ability to reveal complexity that cannot be uncovered from quantitative surveys. This approach obtains descriptions of strongly held attitudes and behaviors which informs research and intervention in regard to the use of medication among of older adults.

<u>Future Research:</u>

Results of this study suggest several different directions that researchers might pursue in the future. Replicating this study among various groups of older adults could help confirm or disconfirm the results of this study and may identify other themes not described here. Future studies may wish to examine each theme in more detail in with different contexts. The proposed theme framework in this study could help guide future research. It is the position of the researcher that reproducing this study on a larger scale would reduce the limitations of this study and thus produce results that are more easily generalized to wider populations.

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Appendix A

CONSENT FORM

Lesya Zubach 611-937 Jefferson Avenue Winnipeg, Manitoba R2P 1H9 Ph: (204) 633-8496 E-mail: Lesya.Zubach@gov.mb.ca

Research Project Title: "Perspectives on the Use of Medication in Aging Populations".

Researcher: Lesya Zubach (M.Sc. Candidate)

Sponsor: None

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of Study

This research study will explore attitudes and practices regarding medication use by aging population, and assess if there are any ways to improve the effectiveness of medication use from multiple perspectives.

Study Procedures

My proposed research project is a qualitative case study. I plan to interview five individuals age 65 and over, who are taking at least 5 prescription medications or over-the-counter medications, who reside in a community and five individuals age 65 and over with disabilities who are taking at least 5 prescription medications or over-the-counter medications, who reside in a community about their perceptions with respect to the use of their medications. Interviews will be conducted in a quiet setting of their choosing, and at time convenient for the participant. The interviews will be recorded and it is estimated that each interview will take approximately 30-40 minutes to complete. Short notes will be taken during the interview process. There will be no deception or deliberate withholding of essential information in this study. Verbal or written feedback will be available to the participant upon request once the study has been completed.

<u>Risks and Benefits</u>

There are no known risks to participants in this study. There will be no penalty if a participant chooses to withdraw from the study; instead, another participant will be sought. There may or may not be direct benefit to you participating in this study. I hope the information learned from this study will benefit other elderly people in the future.

<u>Costs</u>

All the procedures, which will be performed as part of the study, are provided at no cost to you.

Payment for participation

The research subjects will receive no financial compensation for their participation in this study.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law, according to provisions of the Personal Health Information Act. All study related documents will bear only your assigned study number and/or initial.

Dr. Christine Blais, a University of Manitoba professor will have access to my written field notes and transcripts. All notes and tapes will be kept in a locked cupboard in a secure setting and will be destroyed after the study is completed.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate and you may withdraw from the study at any time.

Questions

You are free to ask any questions that you may have about your rights as a research participant. For questions about your rights as a research participant, you may contact The University of Manitoba, Human Ethics Secretariat at (204) 474-7122.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Researcher: Lesya Zubach at 204-633-8496 Supervisor: Dr. Christine Blais at 204-474-6209

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature

Date

Participant's Printed Name

Researcher and/or Delegate's Signature

Date

Appendix B

Interview Guide

	Question	Rationale		
1	What you can you tell me about yourself? -family	 engaging with an interview; gaining an interest in a dialog; single individual needs more assistance with using medications; children/spouse 		
	-education, work -medical condition/disability	can provide help as caregivers; -educated individual can have a better concept in research of medications; - knowledge and experience help to accept		
2	Do you live alone or together with	the concept of using medication -independent living; assistance		
3	Will you tell me a little bit about which medications you take?	-knowledge and experience help to accept the concept of using medication		
4	Do you do any research about medications? Do you like to know about medications you take?	-indication of personality type (self- learning, curiosity, interest, research level)		
5	Do you know why you take these medications? What concerns do you have about using these medications?	-full dependence on caregiver or perception of responsibility of taking one's own medications		
6	Have you ever had bad or odd experiences with medications use? Can you tell me about this?	- frustrations, lack of knowledge; personal experiences		
7	Do you buy and take your medications by yourself? If not, who helps?	-responsibility for managing of drug regime or depending on caregivers		
8	Please, tell me about your experience of receiving help with your medications if any.	-responsibility for managing of drug regime or depending on caregivers		
9	How often do you see your doctor? Do you ask him questions?	-personal experiences		
10	Do you think you get enough help managing your medications? If not, what do you feel you need help with, and why?	-satisfaction and self-confidence in relation of medication use; comfort level		
11	Do you feel restricted in your daily activities because of your medical condition?	-impact of medical condition or impairment		
12	Do you think medications improve your quality of life? How do you feel generally?	-attitude toward of medications use		

Appendix C

Pseudonym

Interview Checklist

	YES	NO
Seniors – aging with disability		
Seniors – aging into disability		

Living Arrangements:

- 1. Alone -----
- 2. With spouse -----
- 3. With Children -----
- 4. Other -------------

Demographic Information:

1. Date of Birth -----2. Gender 3. Marital Status -----4. Education -----5. Profession ______

Medications:

- 1. Prescriptions -----
- 2. OTC _____
- 3. Other -----

Help with medications:

- 1. Homecare -----
- 2. Family ------
- 3. Other ------

Doctor/Pharmacist:

- 1. Number of doctors (family, specialist etc) ------
- 2. Number of pharmacies (one or more)

Appendix D

APPROVAL CERTIFICATE

14 November 2008

TO:	Lesya Zubach Principal Investigator	(Advisor C. Blais)
FROM:	Wayne Taylor, Chair Joint-Faculty Research Ethics Board (JFREB)	
Re:	Protocol #J2008:133	

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

"Perspectives on the Use of Medication in Aging Populations"

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), <u>including the Sponsor name</u>, before your account can be opened.

- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines. Appendix E

Department of Disability Studies University of Manitoba

Participants needed to take part in a study:

Perspectives on the Use of Medication in Aging Populations

As a participant in this study, you have to be:

- 1. Older adult age 65 and over.
- 2. Have a disability or medical condition developed before age 65 or after age 65.
- 3. Take five or more prescriptions and/or over-the-counter medications and live in a community.

All the procedures, which will be performed as part of the study, are provided at no cost to you. Participation is voluntary.

Your participation would involve one hour interview about your experiences and practices regarding medication use.

For more information about this study, or to volunteer for this study, please contact: *Lesya Zubach* (*researcher, M.Sc.Candidate*) at 204-633-8496 Email: <u>Lesya.Zubach@gov.mb.ca</u>

This study has been reviewed by, and received ethics clearance through, the University of Manitoba, Joint Faculty Research Ethics Board

Appendix F

Subject	Relationship with Health	Drug Management	Attitude	Medical	Knowledge/and Experience
	Care Provider			Disability	
G1S1F					
G1S2F					
G1S3M					
G1S4M					
G1S5M					
Total					
G2S1F					
G2S2F					
G2S3F					
G2S4M					
G2S5M					
Total					

Interview Evaluation Guide for Independent Validators

Guidelines for Validators

Please complete the following table for all 10 participants. Under the following headings, please

list what theme you believe to be the most important.

Initials:

After completing above table for all 10 participants, please complete the following sections:

Thinking of G1S1, G1S2, G1S3, G1S4, G1S5, please tell me the number one theme in respect to:

-relationship with health care provider
-drug management
-attitude
-medical condition/disability
-knowledge/experience

Thinking of G2S1, G2S2, G2S3, G2S4, G2S5, please tell me the number one theme in respect to:

-relationship with health care provider
-drug management
-attitude
-medical condition/disability
-knowledge/experience

Thinking of G1S2, G1S3, G1S4, G1S5, G2S4, please tell me the number one theme in respect to:

-relationship with health care provider
-drug management
-attitude
-medical condition/disability
-knowledge/experience

Thinking of G1S1, G2S1, G2S2 G2S3, G2S5, please tell me the number one theme in respect to:

-relationship with health care provider
-drug management
-attitude
-medical condition/disability
-knowledge/experience

Thinking of G1S1, G1S2, G2S1, G2S2, G2S3, please tell me the number one theme in respect to:

-relationship with health care provider
-drug management
-attitude
-medical condition/disability
-knowledge/experience

Thinking of G1S3, G1S4, G1S5, G2S4, G2S5, please tell me the number one theme in respect to:

-relationship with health care provider
-drug management
-attitude
-medical condition/disability
-knowledge/experience