

The meaning of multiple medication use in adults: A qualitative study

Carolyn Dyer, BKIN (Hons)

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Supervisor: Dr. Jarold Cosby, PhD

Faculty of Applied Health Sciences  
Brock University  
St. Catharines, ON

Carolyn Dyer© July 2014

## **Abstract**

Over half of prescribed medications are not taken as prescribed, resulting in health and economic consequences. Using constructivist grounded theory, 15 interviews were conducted to develop a theory on understanding the medication adherence choices of individuals, who were between the ages of 40 to 55, were diagnosed with a chronic condition, and taking three or more medications. The results indicate that participants are engaging in self-management strategies, with massive variance in adherence behaviours. Medications are sacrificed for personal and financial reasons, resonating with feelings of fear for the person's current situation and future. Individuals are struggling with who they have become to who they once were, which becomes related to their medications. Finally, individuals are citing the impact of their physician; citing barriers to communication and Canada's health care system. Participants' experiences provided an understanding of the meanings individuals associate with their medications and how this impacts their decision-making.

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## **Chapter 1: Introduction**

To understand a patient's decision to not adhere to a medication, there needs to be an evaluation of the use of prescription medication as a treatment option. Over half of prescribed medications are not taken as prescribed (Osterberg & Blaschke, 2005), questioning the effectiveness of medication as a treatment option. Non-adherent behavior is higher in those with chronic conditions as opposed to those with acute conditions (Gibson, Ozminkowski, & Goetzel, 2005; Osterberg & Blaschke, 2005). Medication adherence in those with chronic conditions has been found to be affected by the frequency of the dose- a higher medication frequency is associated with poor medication adherence (McDonald, Garg, & Haynes, 2002; Peterson, Takiya, & Finley, 2003; Townsend, Hunt, & Wyke, 2003). This provides some explanation of why those with chronic conditions exhibit higher rates of non-adherence based on dose frequency. This was reflected in a recent study by the World Health Organization (WHO) which found that adherence was only around 50% for those who with a chronic condition in developed countries and approximately 16% of patients fail to fill a new prescription (Golay, 2011; Kreps *et al.*, 2011; Peterson *et al.*, 2003). Townsend *et al.* (2003) concluded that those with chronic conditions who were required to take multiple medications viewed their drug regimen as a central component to their lives, which resulted in drug regimens being viewed as complex, demanding, and restricting.

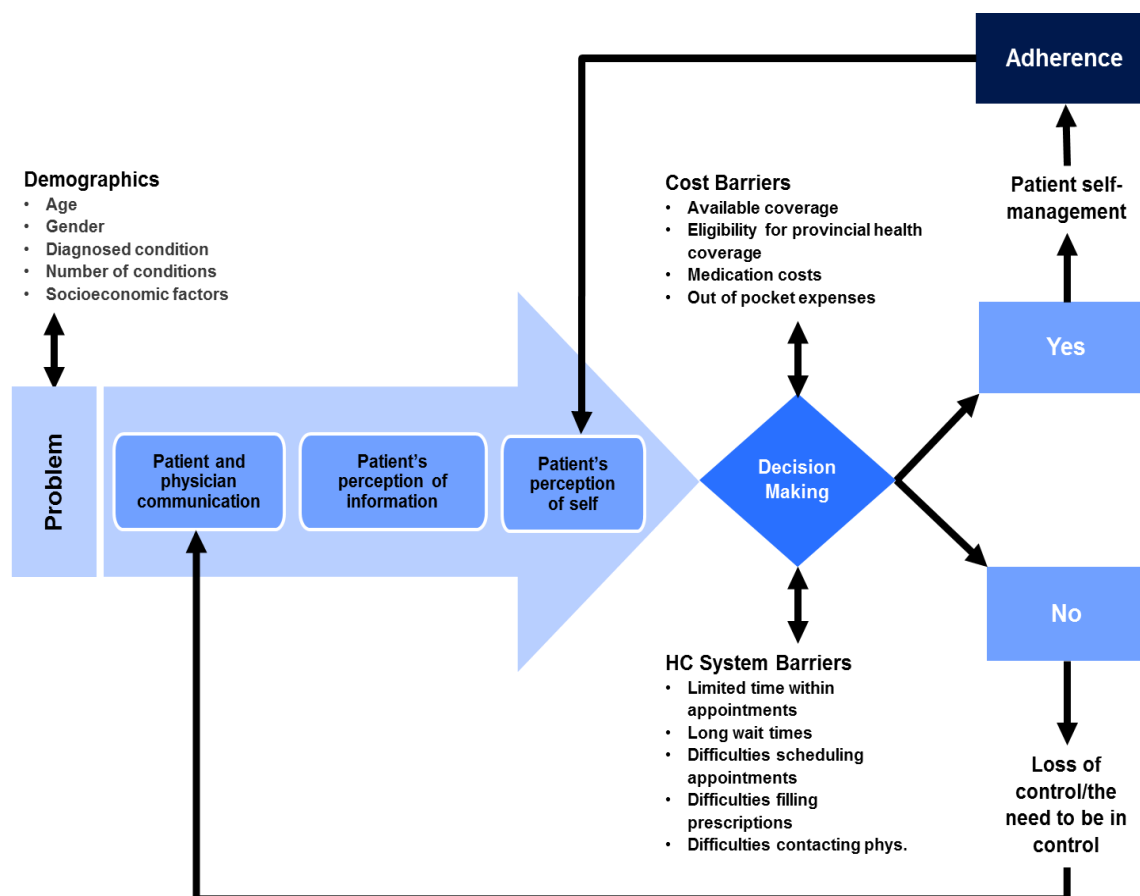
The term 'adherence' is the extent to which the patient's behavior coincides with medical advice or recommendations (Kaufman & Birks, 2009; Golay, 2011; McDonald *et al.*, 2002; Osterberg & Blaschke, 2005; Peterson *et al.*, 2003). The term adherence recognizes the difficulties of following a drug regimen and there is no blame placed on



the prescriber, the patient, or the treatment (Kaufman & Birks, 2009; McDonald *et al.*, 2002). ‘Adherence’ considers physiologically and empirically what optimal care should entail however this term fails to recognize the patient’s concerns and how decisions are made in adhering to a prescribed drug regimen. This becomes problematic since the physician is then unable to conceptualize why patients are choosing not to follow treatment recommendations.

It is essential to evaluate non-adherence when poor adherence can lead to disease progression, complications, side-effects, and in extreme cases death (Townsend *et al.*, 2003; Wang *et al.*, 2011). As a result of poor adherence, treatment outcomes are often impaired and health care costs are increased (Golay, 2011; Kennedy & Morgan, 2006). Barriers have been recognized in adhering to multiple medications such as associated medication costs (Demers *et al.*, 2008; Gibson *et al.*, 2005; Grootendorst, 2002; Kennedy & Morgan, 2006; Law, Cheng, Dhalla, Heard, & Morgan, 2012; Schoen *et al.*, 2007; Schoen *et al.*, 2010), individual factors (Charmaz, 1994; Gallagher, Miller, Cronan, & Groessl, 1997; Holahan, Moos, Holahan, & Brennan, 1995; Kreps *et al.*, 2011; Ledford *et al.*, 2010; Pitman, 1999), patient- physician communication (Ledford *et al.*, 2010; Nair *et al.*, 2002; Osterberg & Blaschke, 2005), and the structure of Canada’s health care system (Demers *et al.*, 2008; Gibson *et al.*, 2005; Golay, 2011; Grootendorst, 2002; Schoen *et al.*, 2010). Figure 1 provides a representation of this literature to summarize all the various factors acting as barriers to medication adherence. This research project will evaluate how specific barriers (i.e. costs, individual factors, patient-physician communication, and Canada’s health care system) influence a patient’s decision-making capacity to adhere to a prescribed drug regimen.

**Figure 1. Factors affecting medication adherence**



### Health Care Costs

When analyzing the effects of cost, individual circumstances need to be considered, specifically the person's available drug coverage, household income, age, diagnosis and number of conditions, and perception of health. In a sample of 3 505 Canadians, 16.2% did not have any form of prescription coverage and were more likely than those with some health coverage to report cost related non-adherence (Kennedy & Morgan, 2006). The Medical Care Act of 1966 and the Canada Health Act of 1984 did not mandate provincial coverage of prescription medications that are taken outside of the

hospital setting and Ontario only offers federal reimbursement to a limited number of groups such as those who have an income of less than \$20 000 (Demers *et al.*, 2008; Grootendorst, 2002). This results in detrimental consequences for patient health and economical consequences for society. If patients are unable to afford their prescribed medication, which may cause their condition to progress, patients may have no choice but to seek other self-management strategies such as alternative medicine. This is concerning when adherence to medications for those with a chronic condition has been the primary means of reducing the risk of relapse or complications and is associated with better health outcomes (Gibson *et al.*, 2005; Golay, 2011).

When reflecting on what specific demographics are exhibiting non-adherence behaviours, it is clear that those with a lower household income are more likely not to adhere to a prescribed drug regimen because of cost restrictions (Golay, 2011; Kennedy & Morgan, 2006; Law *et al.*, 2012; Schoen *et al.*, 2007; Schoen *et al.*, 2010). However, Kennedy and Morgan (2006) found that 34.2% of Canadians in the lowest quintile of household income (approximately less than \$20 000) reported non-adherence due to drug costs compared to only 7.6% in the highest quintile. Schoen *et al.* (2010) also concluded in a sample of 2 316 Canadians that 18% of individuals who were considered to have a ‘below average’ income experienced a barrier to health care because of cost versus 6% of individuals who were considered to have an ‘above average’ income. While Law *et al.* (2012) found in a sample of 10 898 Canadians that 10.5% who had an income of \$40 000 to \$79 999 with some form of coverage reported cost related non-adherence compared to 20.5% who had an income of less than \$20 000 with no medical insurance.

It is evident that those with a lower household income are displaying higher rates of non-adherence due to costs but non-adherence was still taking place in those with a higher household income who have drug coverage to assist with health care expenses. The literature has been unable to provide a basis of why non-adherence is taking place among those who have the financial ability to afford their medication. This provides a further rationale of the importance of evaluating the choices individuals of varying incomes are making in adhering to their prescribed drug regimen.

### **Individual Factors**

Different reasons are cited by men and women in exhibiting non-adherent behaviors (Charmaz, 1994; Gallagher *et al.*, 1997; Holahan *et al.*, 1995; Pitmman, 1999). Despite the fact that some literature has been able to exemplify gender differences occurring in those with chronic conditions (Artinian & Duggan, 1995; Asbring, 2001; Charmaz, 1994; Gallagher *et al.*, 1997; Holahan *et al.*, 1995; Pittman, 1999; Sharpe *et al.*, 1991), both males and females will be included within this research study. This will be explained in further detail within the methods section.

The decision making process of individual's with a chronic condition between the ages of 40 to 55 must be further evaluated in providing insight to the measures that should be taken to improve medication adherence. It is essential to focus on this age group specifically because of the limited amount of literature available on this age bracket who are considered to be relatively young to be on multiple medications (Tinetti *et al.*, 2004; Townsend *et al.*, 2003). Age will be considered in further detail when reviewing barriers associated with medication adherence.

### **Patient-Physician Communication**

A typically cited barrier pertaining to adherence rates is the ability of physicians to candidly communicate with patients and encourage medication adherence (Golay, 2011; Kreps *et al.*, 2011; Ledford *et al.*, 2010; Osterberg & Blaschke, 2005). However, this poses a challenge for physicians if patients are purposely choosing not to communicate with their physician, which limits the ability of physicians to understand the choices patients are making in adhering to their drug regimen. Kennedy and Morgan (2006) concluded that patients are at greater risks for non-adherence if they have minimal interactions with their physician. High quality and cost effective treatment will be best achieved if there is a partnership between the patient and the health care provider (Kaufman & Brinks, 2003).

### **Canada's Health Care System**

Finally, the structure of the health care system must be evaluated in determining the effectiveness of the availability of treatment and how this is impacting patient's decisions regarding adherence to a drug regimen. The choices made by patients have to be reviewed to ensure that health interventions can be modified according to the patient's values and beliefs.

### **Medication Adherence Interventions**

Health interventions that have been implemented to improve medication adherence have focused primarily on clinical outcomes and there has been minimal focus on understanding the decision-making process patients are making in choosing to adhere to their prescribed medications (Britten, 2003; Kreps *et al.*, 2011; McDonald *et al.*, 2002). Hypothetically speaking, if a patient were diagnosed with a chronic condition and

expected to take multiple medications over an extended period time, yet purposely chose to only adhere to certain medications, there needs to be an explanation of why this is occurring. Golay (2011) has found that adequate adherence results in more cost-effective use of health care resources and an enhanced quality of life. If there is an expectation to improve medication adherence, then interventions cannot be based solely on clinical outcomes. Interventions need to be multidimensional in addressing the patient's choices and providing a rationale of why non-adherent behaviour is occurring.

### **Qualitative Inquiry**

To elicit patient's experiences qualitative research is an ideal method. The purpose of using qualitative research is it allows the researcher to focus on the experiences of participants to determine how meanings are constructed through and in culture, and to discover variables as opposed to testing variables (Corbin and Strauss, 2008). Qualitative data provides depth and details, which is best obtained through the use of interviews (Patton, 1990). Qualitative interviewing is a useful approach within the health care setting and through the use of interviews it will allow participants to speak of their decisions regarding medication adherence, to learn their judgements, and "to capture the complexities of their individual perceptions and experiences" (Patton, 1990, p. 205). Therefore, a qualitative and subjective basis will be the most appropriate method used for understanding the choices made by individuals diagnosed with a chronic condition and as a result are required to take multiple medications.

Grounded theory is an ideal approach, as it is a qualitative research method concerned with developing an explanatory theory of basic social processes (Creswell, 2007; Moustakes, 1994; Patton, 1980; Patton, 2008; Starks & Trinidad, 2007).

According to Moustakes (1994) the final objective of grounded theory is to construct an integrated theory that is developed by focusing on elements of other's experiences and from these elements a theory is developed that enables the researcher to understand an individual's particular experience. Interviews are an ideal choice for grounded theorists. Interviews elicit subjective worldviews and are very flexible in nature- the researcher can constantly modify the interview guide and pre-determine to some extent what is asked to focus on a certain phenomenon (Holstein & Gubrium, 2003). Grounded theory also depends upon flexibility; grounded theory develops a framework through data collection and the researcher is constantly returning to the field to ask questions that are continually changing to fill in the gaps within the data until themes are clearly submerged within the categories (Holstein & Gubrium, 2003). Thus, grounded theory is a logical method for investigating the decision-making process of individuals with a chronic condition who are required to take multiple medications.

**Purpose:**

The purpose of this study is to develop a theory of the process of decision-making in medication adherence. Specific organizational and individual factors (i.e. the costs of health care, individuality, patient-physician communication, and Canada's health care system) will be analyzed while investigating the influence these factors have on a patient's ability to follow their physician's recommendations. A theory based upon the data will aid decision and policy makers in understanding how decision making works, why it works the way it does, and the impact it has on patients as well health care as a whole (Patton, 1980). Grounded theory analysis can provide physicians with alternative understandings of patient's lay beliefs and actions compared to those offered within the

clinical setting (Charmaz, 1990). Based upon data collection, with a focal point around individual experiences, it will aid in developing a framework for health care providers in understanding the context and the rationale behind a lay person's decisions in adhering to prescribed medications. Once a rationale has been provided for adherent or non-adherent behaviours, a hierarchy will be created exemplifying what factors are primarily affecting individuals while considering the demographic of the person (i.e. diagnosed condition, number of conditions, number of prescribed medications, gender, education, etc.).

### **Research Questions:**

What factors influence the decisions of individuals between the ages of 40 to 55 who are prescribed 3 or more medications in adhering to a drug regimen? Finally, how do these factors influence the decisions patients are making in adhering or not adhering to their prescribed drug regimen?

## **Chapter 2: Review of Literature**

The following section will review organizational and individual factors that can affect an individual's ability to adhere to a prescribed drug regimen. There have been specific barriers that have been recognized in non-adherent behavior, specifically health care costs, individual factors, patient-physician communication, and Canada's health care system. However, these specific barriers have only been considered as single entities, not as co-existing factors. The literature was reviewed and will highlight the gaps within the current research that have failed to recognize the patient's decision-making process in adhering to their physician's prescribed medication treatment. A review of medication adherence interventions was conducted to demonstrate the successes and failures of interventions that have been implemented in an attempt to improve medication



adherence. By reviewing the inconsistencies within previously implemented interventions, the review will aid in providing a framework that can be used by decision and policy makers in understanding the choices made by patients in adhering to a prescribed drug regimen.

## **Health Care Costs in Canada**

### *Effects of policy:*

Canada's ability to mandate the pricing of prescription medications can affect an individual's ability to adhere to a prescribed drug regimen by forcing Canadians to pay a certain amount for health care services. Before discussing the foundations of drug coverage within Canada, it is important to understand key terms that are used when explaining health insurance. 'Beneficiary cost sharing' is the direct charge to the patient while the patient's insurer (assuming the patient has coverage) covers the remainder of the costs (Gibson, 2005; Grootendorst, 2002). Beneficiary cost sharing can take several forms including: premiums, deductibles, copayments, and coinsurance. 'Premiums' are payments made to receive drug coverage and have no relation to drug use while 'deductibles' are the amount of health care costs the beneficiary is responsible for before the insurer has any payments (Gibson, 2005; Grootendorst, 2002). 'Copayments' are a fixed amount paid by the insured as a result of deductibles and coinsurance (i.e. the patient pays \$10 per prescription regardless of the prescription) and 'coinsurance' is a share of a fixed percentage of the drug costs paid by the beneficiary of the healthcare policy (i.e. the beneficiary pays 20% of the prescription costs) (Gibson, 2005; Grootendorst, 2002).

In Canada there is no federal reimbursement or standardization for drug plans; thus each province funds and establishes some form of drug insurance program (Demers *et al.*, 2008; Grootendorst, 2002). This allows provinces to create their own terms and conditions. For example, each province can regulate who is eligible for coverage, the specific medications that are covered, and the amount of beneficiary cost sharing for covered prescriptions (Grootendorst, 2002; Schoen *et al.*, 2010). The payments made by patients vary across the provinces since there is no standardization in prescription costs despite legislation in place that regulates some aspects of Canadian healthcare at the federal level.

The Medical Care Act of 1966 and the Canada Health Act of 1984 do not mandate provincial coverage of prescription drugs that are taken outside of hospital care (Demers *et al.*, 2008; Grootendorst, 2002). This raises numerous concerns when Canada is basing prescription drug coverage on outdated legislation and is not considering that prescription medication is a primary means of treatment for patients. Furthermore, patients are spending less time in hospitals (Schoen *et al.*, 2010), which is forcing patients to pay for prescriptions that otherwise would have been administered within a hospital setting and thus covered. It is necessary for Canada to update this piece of legislation when taking into account that in 2005, \$20.6 billion was spent on outpatient prescription medications, which results in the second largest category of health spending in Canada after hospital expenditures (Demers *et al.*, 2008; Morgan, 2004). Furthermore, of the \$20.6 billion, \$4 billion is due to out-of-pocket expenses made directly by patients (Demers *et al.*, 2008). According to Law *et al.* (2012) most Canadians have some form of coverage yet are still forced to pay for necessary treatment. These out-of-pocket

expenses may provide a rationale of why patients are not adhering to their drug regimen and sacrificing their health due to medication expenses.

In an attempt to reduce prescription costs for patients, most provinces offer separate and more comprehensive coverage for certain medications (Grootendorst, 2002; Schoen *et al.*, 2010). However, Morgan (2004) concluded that provincial drug programs only fund approximately 40% of prescription drugs in Canada since only certain medications are patented and covered under provincial drug funding. When taking into account those with a chronic condition who are required to take multiple medications, this provides minimal reassurance when this group of individuals are recommended to take numerous medications and not even half of their prescription costs are being covered. Furthermore, all provinces have limited the coverage of brand name drugs but instead provide coverage on the lowest costing, interchangeable generic drug (Grootendorst, 2002). If the person wants the brand name drug then he/she is responsible for the difference in costs (Grootendorst, 2002). However, some brand name drugs have been proven to be clinically more effective than its' generic counterpart (Andermann, Duh, Gosselin, & Paradis, 2007; Guberman & Corman, 2000; Sanyal & Datta, 2011). Patients then suffer by either having to pay the additional costs for the brand name or are aware that they are not receiving the best possible treatment by settling for the generic brand due to costs restrictions. This may affect patient's choices in adhering to a prescribed drug regimen and leave the patient questioning what is the 'right' decision?

Provincial health programs have attempted to counter the increase in prescription medication expenditures by implementing higher copayments, reducing reimbursement levels, placing caps on the number of covered prescriptions, and restricting formularies

(Kennedy & Morgan, 2006). However, this is not an optimal solution for those with chronic conditions who are required to take multiple medications, therefore already having higher associated costs. Ontario has implemented more control mechanisms to limit drug use to more effective cost options (primarily generic drugs). This may influence those who are diagnosed with a chronic condition in making decisions in determining what medication to take since the most effective cost option may not be the most effective health option.

Since Canada does not have standardized provincial drug programs and restricts reimbursements to a limited number of groups, individuals are sacrificing their health due to the increasing costs of medications. One of the guiding principles of Canada's health care system is that 'all Canadians should have equal access to health care benefits' (Demers *et al.*, 2008). However, this is clearly not taking place when it has been shown that beneficiary cost sharing can lead to poor health outcomes by forcing patients to pay a certain amount for a prescription (Grootendorst, 2002). Direct charges disproportionately affect those with low incomes and the 'working poor' that have no form of drug coverage; as a result health is being sacrificed. Finally, low income individuals have a larger modifiable burden of illnesses and thus face the consequences of direct charges more so than those with a higher income who are in better health (Grootendorst, 2002). Literature is citing that provincial drug plans are preventing individuals from taking their prescribed medication (Demers *et al.*, 2008; Grootendorst, 2002; Schoen *et al.*, 2010). However, there needs to be a further understanding of the extent to which an individual's drug coverage is affecting the patient's decision-making capacity to adhere to their medications.

People lacking insurance for prescription medications was associated with a more than fourfold increase in cost related non-adherent behaviors than individuals with some form of coverage (Law *et al.*, 2012). For example, 26.5% exhibited non-adherence who had no prescription drug coverage versus only 6.8% did not adhere who had partial coverage for prescription drugs (Law *et al.*, 2012). In a sample of 3 505 Canadians, 16.2% did not have any form of prescription coverage and were more likely than those with some form of insurance to report cost related non-adherence (Kennedy & Morgan, 2006). Schoen *et al.* (2010) concluded that 10% of the general population had no form of health coverage and the rates of average coverage declined with household income resulting in cost related non-adherence.

As previously outlined, provincial drug programs have been implemented to assist those who qualify for social assistance and who have a lower household income but this is not consistent with what is being said within the literature. Cost is being cited as a barrier by those who do qualify for social assistance and who have a lower household income. This leads one to question, why is cost being cited as a barrier to medication adherence if financial funding is being provided. This further supports the importance of investigating the need to understand the decisions made by individuals with chronic conditions who may categorize themselves as having minimal coverage with a lower household income. Grounded theory is an ideal method in generating a theory that will aid physicians in understanding the effects of medication costs (Charmaz, 1990; Charmaz, 1994), which has been exemplified in affecting individuals of varying incomes, available drug coverage, diagnosis of condition, and perceived quality of health.

However, to further understand the social processes of medication adherence and generate a theory that is integrated – individual factors need to be considered.

*Health care expenses:*

To understand a patient's experiences, it is essential to consider the barriers in adhering to one's medications. Cost was viewed as a barrier to medication adherence and may be the most important factor that affects policy interventions (Gibson *et al.*, 2005). Cost can impact the choices patients choose to make to adhere to a drug regimen because of the restrictions felt by the price of medications; specifically the perceived notion of the costs associated with generic versus brand name drugs. However, the economy theory states that if an individual were aware of the benefits and adverse effects of a drug, one will consume an optimal amount of the drug based upon income constraints and knowledge of the drug (Gibson *et al.*, 2005). The economy theory further concludes that when individuals with a low income are faced with an increase in direct charges, this group will relinquish more drugs than those with a higher income (Schoen *et al.*, 2010). This is subject to the physician's ability to relay the importance of medication adherence while considering cost as a restriction when prescribing a medication specifically for those who have a minimal income. If cost is affecting an individual's ability to make decisions regarding adherence to a prescribed drug regimen, then there needs to be a better conceptualization of the effects of costs according to individual circumstances.

In 2003, Canadians out-of-pocket expenses on prescription drugs totalled approximately \$16 billion (Morgan, 2004). In 2010, out-of-pocket payments totalled \$4.6 billion or approximately 17.5% of total spending on prescription drugs in Canada (Law *et al.*, 2012); the decline in spending can be partially attributed to the passing of Bill

102 in Ontario in 2006 which mandated the pricing of generic drugs. However, Canadians are still spending a large amount of money on prescription drugs, providing cause for why medication adherence may not always be a viable option. The out-of-pocket payments made by Canadians may be affected by the need for a brand name drug over a generic drug based on literature outlining that brand name drugs can be more clinically effective than generic drugs (Andermann, Duh, Gosselin, & Paradis, 2007; Guberman & Corman, 2000; Sanyal & Datta, 2011).

In 2001 to 2004 the mean copayments for generic drugs increased by 42.9% (from \$7 to \$10), preferred brand name drugs rose 61.5% (from \$13 to \$21) and non-preferred brand name drugs increased 94.1% (from \$17 to \$33) (Gibson *et al.*, 2005). Despite the increase in drug costing, there has been a resistance to generic drugs by patients. Patients prefer brand name over generic drugs based upon the perception of increased quality and effectiveness in brand name drugs (Gibson *et al.*, 2005). Expenditure growth in Canada has been attributed to higher prescription rates resulting in an increase in medication use specifically brand name drugs, which are more costly options (Demers *et al.*, 2008; Kennedy & Morgan, 2006; Morgan, 2004). This is problematic since patients are restricting the consumption of their prescribed medications due to cost, yet are willing to pay more for a brand name drug sacrificing adherence in return.

The importance of understanding patient's individually is evident when reflecting on the effects of the costs of prescription medications. One in 10 Canadians have not filled a prescription, renewed a prescription, or have tried to make a prescription last longer because of out-of-pocket expenses (Law *et al.*, 2012). Higher prices in medications results in lower consumption. It has been demonstrated that patients will

look for substitutes for their medications and will be more inclined to take these substitutes instead of the prescription because of affordability (Gibson *et al.*, 2005; Law *et al.*, 2012). If a strategy is developed that involves improving patient's health while saving money, individuals may be more inclined to adhere. It is apparent that the price of a drug regimen affects an individual's ability to adhere to prescribed medications, especially those between the ages of 40 to 50 who are diagnosed with more than 2 chronic conditions and perceive their health as being 'poor'.

### *Demographics*

#### *Age:*

It is important to recognize individual differences when conceptualizing how the costs of medications can restrict a person's decision to adhere to a prescribed drug regimen. Law *et al.* (2012) conducted a study that included 10 898 participants from 10 Canadian provinces and concluded that 9.6% of Canadians engaged in non-adherence due to cost. This type of non-adherence varied with age, number of chronic conditions, perception of one's health, household income, and drug coverage. The prevalence of cost related non-adherence was highest in those between the ages of 35 to 44 at 11.4% and 45 to 64 at 10.8% while only 4.8% of participants over the age of 65 did not adhere due to cost (Law *et al.*, 2012). Kennedy and Morgan (2006) also concluded in a sample of 3 505 Canadians, that 17.7% of adults aged 35 to 55 and 16.7% aged 45 to 55 reported non-adherence due to costs compared to only 8.2% of adults over the age of 75.

The above findings are supported by Townsend *et al.* (2003), who found that individuals between the ages of 40 and 50 were expected to be at the peak of their wage earnings; yet this group demonstrated the greatest sensitivity to cost when adhering to their drug regimen. One may speculate that this specific age bracket is exhibiting cost



related non-adherence because of available drug coverage, as earlier indicated the ‘working poor’ have too much income to qualify for social assistance but are employed in sectors that do not provide health benefits. Furthermore, those between the ages of 40 to 50 may not be prepared to recognize or accept being labelled as ‘ill’ and thus are more defiant against recommended treatments (Auduly *et al.*, 2012; Charmaz, 1994). When understanding the process of decision-making, it is necessary to examine the choices this specific group is making if cost is being viewed as a barrier despite the literature outlining that this group should be at the peak of their wage earnings.

*Diagnosis and perception of condition:*

Age is not the only individual factor that needs to be considered in relation to the costs of medication. Grootendorst (2002) found that adults who reported chronic pain which limited activity were 29.9% more likely to report cost related non-adherence versus only 12.4% of adults with acute pain who reported cost as a barrier to adherence. Law *et al.* (2012) also concluded that individuals who have been diagnosed with more than two chronic conditions were 12.4% less likely to adhere to a drug regimen due to cost compared to 11.2% when diagnosed with one chronic condition and 8.2% when not diagnosed with a chronic condition. Those who are diagnosed with more than two chronic conditions will most likely be required to take more prescribed medications and have more associated costs. However, this specific group who are most in need of medication to manage various medical conditions are unable to do so because of the cost of medications.

Finally, participants were asked to rate their perception of their own health. Those who classified their health as being ‘fair or poor’ had the highest cost-related non-

adherence at 20.1% compared to ‘good’ at 10.4% and ‘excellent or very good’ at 6.9% (Law *et al.*, 2012). Grootendorst (2002) also had similar findings with adults who perceived their health to be ‘fair or poor’ were 29.9% more likely to report non-adherence due to costs compared to only 12.4% of individuals who assessed their health as being ‘good, very good, or excellent’. This is ironic since those who require health care the most are citing cost as a barrier and are significantly less likely to adhere to a drug regimen despite the need for it.

*Income:*

In 2000, medications for citizens in Ontario with social assistance and low annual income households (less than \$20 000) had no premiums, deductibles, and no beneficiary contribution (Grootendorst, 2002). Copayments and coinsurance were \$2.00 per prescription if a person qualified for social assistance or had a household income below \$20 000 (Grootendorst, 2002). However, this system does not consider the ‘working poor’, who are individuals that make more than \$20 000 but unfortunately are not employed by a company that provides healthcare benefits (Schoen *et al.*, 2010). Thus, do not qualify for the provincial drug plan; as a result they have no coverage (Schoen *et al.*, 2010). Research has concluded that those who qualify for social assistance and have a household income of less than \$20 000 (thus qualify for provincial drug assistance programs) are most affected by out-of-pocket payments of prescription drugs and limit drug use as result (Demers *et al.*, 2008; Kennedy & Morgan, 2006; Law *et al.*, 2012). Furthermore, a low household income was associated with an increase in cost related non-adherence compared to a high household income (Grootendorst, 2002; Kennedy & Morgan, 2006; Law *et al.*, 2012; Schoen *et al.*, 2007; Schoen *et al.*, 2010). Law *et al.*

(2012) found that annual household incomes of \$20 000 or less were 20.5% more likely to not adhere to their prescribed medications due to cost versus household incomes of \$40 000 to \$80 000 that were only 10.5% likely not to adhere to their drug regimen because of costs. Kennedy and Morgan (2006) also concluded that household incomes within the lowest quintile were 34.2% to report non-adherence due to prescription costs compared to only 7.6% in the highest quintile who cited cost as a barrier to medication use. This demonstrates that numerous groups are affected by Ontario's provincial drug plan regardless if one qualifies for provincial drug funding or not, cost was still being cited as a barrier. This is not only affecting a person's abilities to make choices pertaining to medication adherence but limiting the choices to be made.

### **Individual Factors in Medication Adherence**

#### *Commitment to chronic condition:*

After reviewing the effects of health care costs, it is evident that specific demographics can influence medication adherence behaviours. To evaluate the factors that influence decision-making pertaining to medication adherence, barriers that directly affect the individual should be assessed. For the patient with a chronic condition, adhering to a prescribed medication it is not a single decision but is a daily decision to which a commitment is extremely challenging. Chronic conditions places a different set of demands on a patient than does an acute condition – living with a chronic condition requires continued decision-making and adjustments to changing circumstances for both the patient and loved ones (Ledford *et al.*, 2010; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). According to Kreps *et al.* (2011), Ledford *et al.* (2010), and Zhao, Villagran, and Kreps (2011) the two most common barriers to medication adherence were the concern about

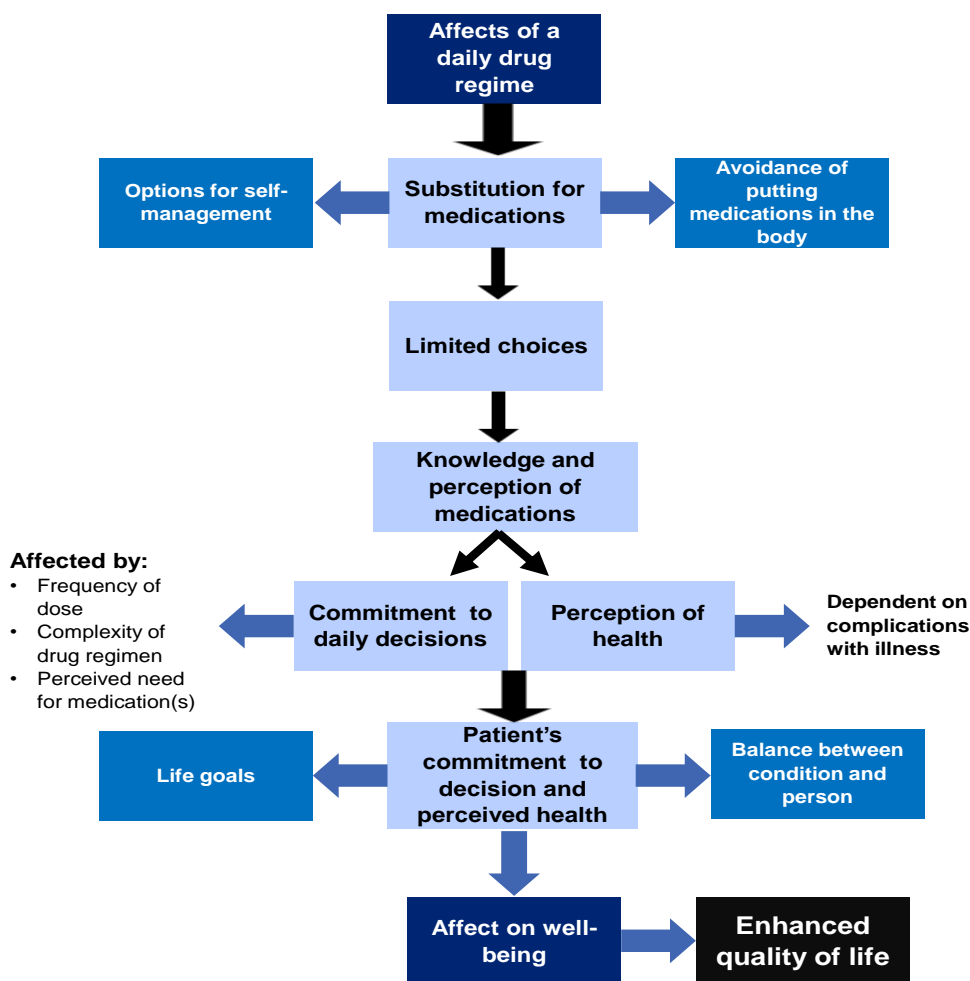
the prescribed medication and the perceived need for the medication (medication commitment).

Concern of one's health was dependent on the side-effects and the impact it had on a patient's daily life (Kreps *et al.*, 2011; Ledford *et al.*, 2010; Zhao *et al.*, 2011). As well, patients compared the side-effects with the symptoms experienced prior to treatment (Kreps *et al.*, 2011; Ledford *et al.*, 2010; Zhao *et al.*, 2011). 57% of participants (n=17 males, 13 females; mean age of 46) reported moderate to strong feelings about the need for medications yet recognized their drug regimen as a barrier (Kreps *et al.*, 2011). Commitment to one's drug regimen was dependent on the perceived need for the medication (diagnosis belief and perceived need for the prescribed therapy) and the effectiveness of the medication (treatment belief) (Ledford *et al.*, 2010; Zhao *et al.*, 2011). Participants within Ledford *et al.* (2010) study spoke of not understanding why he/she were being prescribed medication that did not pertain specifically to their condition and did not see the point in taking it. However, others recognized that if one went a few days without taking their medication he/she would experience pain but only then would he/she recognize the effectiveness of their medication and then be willing to take their medication (Ledford *et al.*, 2010).

When patients with a chronic condition make decisions about their medication use, there must be an optimal trade-off between the benefits and the harm within the context of the patient's health priorities (Ledford *et al.*, 2010; Tinetti *et al.*, 2004). Medications are purposefully prescribed by health care professionals to aid in the management of a medical condition. However, for some the side-effects of prescribed medications outweigh the benefits. Furthermore, patients have raised concerns about

being prescribed multiple medications and the long-term effects this will have on their body, which has prevented individuals from adhering to their prescribed drug regimen (Asbring, 2001; Kralik, 2012; Ledford *et al.*, 2010). See Figure 2, which is based on an accumulation of what has been outlined in the literature (Asbring, 2001; Kralik, 2012; Kreps *et al.*, 2011; Ledford *et al.*, 2010; Zhao *et al.*, 2011).

**Figure 2. Effects of daily medication use on adherence behaviors**



*The search for normality:*

Commitment and concern to a patient's drug treatment was also dependent upon the person's beliefs and values. Audulv *et al.* (2012) concluded that patient's beliefs and

values included the participants' views of themselves (i.e. their abilities to manage their condition), normality, and how one "should" live with a chronic condition. This study consisted of 21 participants who were diagnosed with ischemic heart disease, rheumatic diseases, chronic kidney failure, inflammatory bowel disease, multiple sclerosis, and/or diabetes often in conjunction with other long-term conditions (asthma, breast cancer, high blood pressure, heart conditions, chronic pain, or fibromyalgia).

Many participants spoke of the need to be a "good patient"; for example, one participant spoke of how a "good" diabetic should live and the importance of balancing one's own life within the condition (Auduly *et al.*, 2012). Yet research has been unable to exemplify to what extent individuals sacrifice certain life goals due to their condition. As a result, how this is affecting the choices individuals are making. More importantly, how can health care professionals help their patients maintain a balance between the patient's life goals while managing their condition? If self-management strategies can be easily integrated into a patient's life, an increase in medication adherence may be a viable option. Wagner *et al.* (2005) concluded that self-management was an active process that requires patients to make day-to-day decisions to manage their medical condition and that these decisions play a vital role in managing chronic conditions. The effectiveness and quality of integrating self-management strategies into one's life is a strong determinant of health outcomes (Wagner *et al.*, 2005). This may be challenging for patients to achieve if there cannot be a balance between the person and the medical condition.

Participants within Auduly *et al.* (2012), Kralik (2002), and Townsend *et al.* (2003) studies also spoke of the search for "normality". Many participants purposely limited their search for information about their condition because he/she did not want to

identify themselves as an “ill” person. For some, normality could only be achieved by following a complex drug regimen to relieve distressing symptoms (Townsend *et al.*, 2003), while some purposely did not want to follow a drug regimen because it was not possible to live a “normal” life (Auduly *et al.*, 2012). One participant spoke of how, “it [the rheumatism] takes up too much space as it is, without becoming an illness” (Auduly *et al.*, 2012, p.341). This was also exemplified within Asbring (2001) and Charmaz’s (1994) study of the importance of maintaining the life patients once had before being diagnosed with a medical condition.

It is evident individuals within these studies who were diagnosed with a chronic condition were unable to accept their condition and are purposely choosing not to accept information about their condition in return for a ‘normal’ life. However, individuals are then sacrificing their health and as previously outlined by not adhering to treatment, it will result in potential enhanced side-effects and poor disease progression (Golay, 2011; Townsend *et al.*, 2003; Wang *et al.*, 2011). Thus, how can patients expect to achieve ‘normality’? Research has been unable to clearly document what normality is for those with multiple conditions who are between the ages of 40 to 55 and are already considered to be relatively young to be diagnosed with a chronic condition (Townsend *et al.*, 2003). Grounded theory will aid in generating a theory that will help explain or provide a framework validating the influence that the search for normality can have on the decisions made by individuals who are required to take multiple medications (Charmaz, 1990). The search for normality may cause patients to question their identity since patients are trying to integrate their disease into a life one previously had, which may not be a viable option if medication adherence is going to take place.

*Patient identity and experience living with chronic condition(s):*

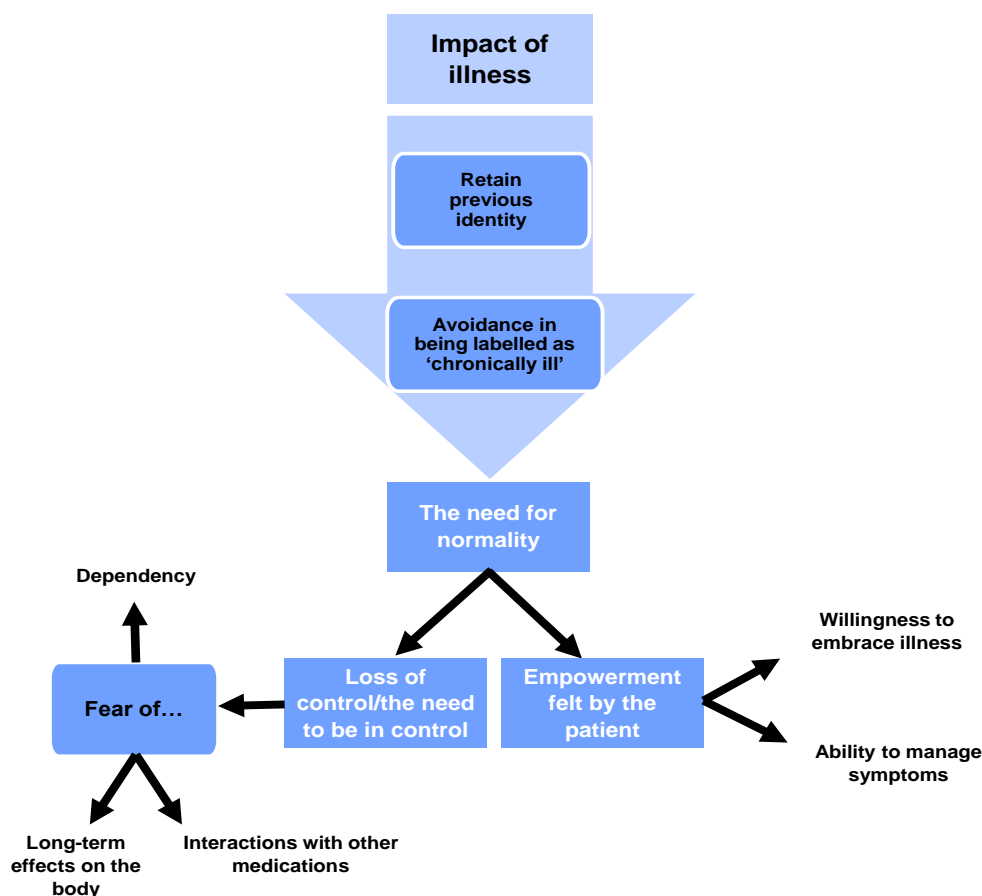
Charmaz (1994) considered the effects of being diagnosed with a chronic condition, which requires multiple medications, can have on a male's identity. Charmaz (1994) found that when men experienced a chronic condition it threatened their identity especially in middle-aged men; this was also found by Asbring (2001) in middle-aged women diagnosed with a chronic condition. Men faced identity dilemmas such as risking activity versus forced passivity, remaining independent versus becoming dependent, maintaining dominance versus becoming subordinate, and preserving a public persona versus acknowledging private feelings (Charmaz, 1994). It is evident that being diagnosed with a chronic condition can threaten a men's masculine identity since they are not in complete control of something (i.e. personal health) that they once were.

Asbring (2001) and Kralik (2002) also found similar findings to Charmaz (1994) in women living with a chronic condition. Women within Asbring (2001) and Kralik's (2002) study spoke of the loss of control they felt over life circumstances and the need to retain their previous identity, which as previously cited was also experienced by males diagnosed with a chronic condition. Living with a chronic condition meant physical, psychological, social, and economic losses yet it also entailed taking calculated risks, surrendering security, making choices, and taking risks (Kralik, 2002). Unlike findings from Charmaz (1994), women embraced their condition(s) and reconstructed their identity to gain a sense of empowerment and control, rather than being a 'victim' of their health (Asbring, 2001; Kralik, 2002). However, it was never outlined how power and control was achieved within a participant's life and to what extent this affected choices made in adhering to their physician's recommendations. See Figure 3 for a summary of



the literature with a focal point in understanding the patient has a whole (Asbring, 2001; Charmaz, 1990; Charmaz, 1994; Kralik, 2002; Kreps *et al.*, 2011; Ledford *et al.*, 2010). By implementing grounded theory, it will allow individuals to reflect on their experiences of being ill and more importantly the diversity of each experience (Charmaz, 1990). It is important to consider how a chronic condition and the management of comorbid conditions affect an individual's identity. This may indirectly affect the choices made by patients in adhering to their prescribed drug regimen.

**Figure 3. How the condition impacts 'the person' and 'the patient'**



It is essential to analyze why patients are choosing not to adhere to their prescribed medications despite the need for treatment in managing their medical condition. Kreps *et al.*'s (2011) study included 30 participants who were diagnosed with

a chronic condition and who self-reported not adhering to their drug regimen. The majority of participants became concerned if side-effects started to appear after being dependent on their medication for a longer period of time; this exemplified how patients were in tune with their health but would only take action when it directly affected their well-being.

Patients who claimed that non-adherence was due to the medication side-effects, based this behaviour upon the impact their medications had on their day-to-day activities and if symptoms were present that pertained specifically to the patient's diagnosed condition (Kreps *et al.*, 2011; Ledford *et al.*, 2010). If symptoms were not manageable and patients experienced unacceptable side-effects, adherence decreased because of the negative experiences associated with the medication (Kreps *et al.*, 2011; Ledford *et al.*, 2010). This resulted in a reduced commitment to the therapy (Kreps *et al.*, 2011; Ledford *et al.*, 2010). However, if symptoms were manageable then there was little concern about the side-effects of the medication. Also, if a patient experienced no side-effects then the patient had a higher conviction that the medication was the ideal treatment and were more likely to adhere (Kreps *et al.*, 2011; Ledford *et al.*, 2011). Prescribed medications play a key role in managing symptoms, allowing individuals to carry out everyday tasks that can become central to one's identity (Townsend *et al.*, 2003). By not adhering to a prescribed drug regimen it not only will affect the individual's ability to perform day-to-day tasks, but will indirectly affect the patient's identity if they are unable to control their health and perform tasks that were once possible.

There have been gaps within the literature that have not been able to clearly demonstrate the extent to which adherence is taking place and how decision-making

directly affects adherence. Kreps *et al.* (2011) study had numerous limitations since participants reported purposely not adhering to their prescribed drug regimen, raising the question of how it can be concluded that participants became concerned about side-effects over an extended period of time if adherence was not taking place. Furthermore, there was no conceptualization if the decision to not adhere to one's treatment was based solely on the medication's side-effects or if other factors played a role in affecting adherent choices. Lewis, Robinson, and Wilkinson (2003) and Townsend *et al.* (2003) concluded that other factors do play a key role in choosing to adhere to multiple medications – participants purposely did not adhere to their drug regimen to avoid putting “pills and potions” into their bodies, which was stemmed from fears of dependency, side-effects, and interactions with other drugs.

Specific factors have been recognized in explaining why patients' haven chosen not to adhere to their medications yet research has failed to outline interventions that could be implemented to counter non-adherent behaviors (Kreps *et al.*, 2011; Ledford *et al.*, 2010; Townsend *et al.*, 2003). However, poor adherence is still affected by the severity and presence of the patient's side-effects. This could be improved if physicians explained the benefits and side-effects of the prescribed medication and would be an ideal intervention option (Golay, 2011; Kreps *et al.*, 2011; Nair *et al.*, 2002; Osterberg & Blaschke, 2005). Also, patients must be willing to actively communicate with their physician about the side-effects experienced, providing physicians with the opportunity to outline the importance of the medication despite the side-effects associated with the prescribed medication. Active communication between a patient and physician has been found to have positive associations with medication adherence (Gold & McClung, 2006;

Kreps *et al.*, 2011; Ledford *et al.*, 2010; Lewis, Robinson, & Wilkinson, 2003; Pittman, 1999; Zhao *et al.*, 2011). However, there is conflicting literature citing communication with physicians has posed as a barrier to medication adherence for patients living with a chronic condition (Golay, 2011; McDonald *et al.*, 2002; Osterberg & Blaschke, 2005; Wagner *et al.*, 2005).

### **Patient-Physician Communication**

#### *The effects of physician communication:*

Physicians must be able to communicate the effectiveness of a proposed treatment and explain to patients the negative side-effects that could occur due to poor adherence (Ledford *et al.*, 2010; Osterberg & Blaschke, 2005). Physicians should be asking patients about experienced side-effects, if the patient understands the purpose of their medications, and explain the benefits of the prescribed treatment (Ledford *et al.*, 2010; Osterberg & Blaschke, 2005). These specific questions can be a tool used by physicians to expose patient's poor adherence and allow patients to raise any concerns regarding their treatment. A study conducted by Nair *et al.* (2002) included 88 patients (mean age was 54; prescribed a minimal of 2 medications), who felt that they received minimal information about their medication and were frustrated that they were not provided with enough information regarding the side-effects and risks associated with their treatment. Participants felt if they had full disclosure about their condition, they could make more informed treatment decisions. In a study of 2 500 respondents, 76.2% wanted full disclosure about all possible adverse effects of their medications (Nair *et al.*, 2002). This validates the influence physicians have in patient's decision making and the importance of providing patients with information regarding their condition and treatment options.

Physician communication may indirectly affect patient's poor adherence by not providing information regarding the patient's condition. Health care providers directly affect patient-related causes of poor adherence by prescribing complex drug regimens, being unable to address patient's concerns about their illness and treatment options, not supporting the patient's treatment decisions, and not considering the patient's lifestyle. As a result, patients are intentionally missing appointments to avoid communication with physicians (Golay, 2011; McDonald *et al.*, 2002; Osterberg & Blaschke, 2005; Wagner *et al.*, 2005).

It is ironic that patients are purposely missing appointments when the literature has cited the importance patients place in communicating with their physician and how physicians are typically the patient's primary source of information (Gold & McClung, 2006; Kreps *et al.*, 2011; Ledford *et al.*, 2010; Lewis *et al.*, 2003; Pittman, 1999; Zhao *et al.*, 2011). This was also reflected in a study conducted by Audulv *et al.* (2012) where participants viewed physicians as their primary source of information and when patients asked their physicians for advice regarding their conditions and did not receive any suggestions, patients automatically concluded that the self-management strategies he/she were implementing were irrelevant. Furthermore, health care providers only gave information about specific self-management strategies (i.e. medication and diet) rather than supporting the patient's ongoing self-management integration (Audulv *et al.*, 2012; Nair *et al.*, 2002). This is a hindrance to patients and affects the choices patients are making in following their physicians recommendations if the patient's efforts are being dismissed.

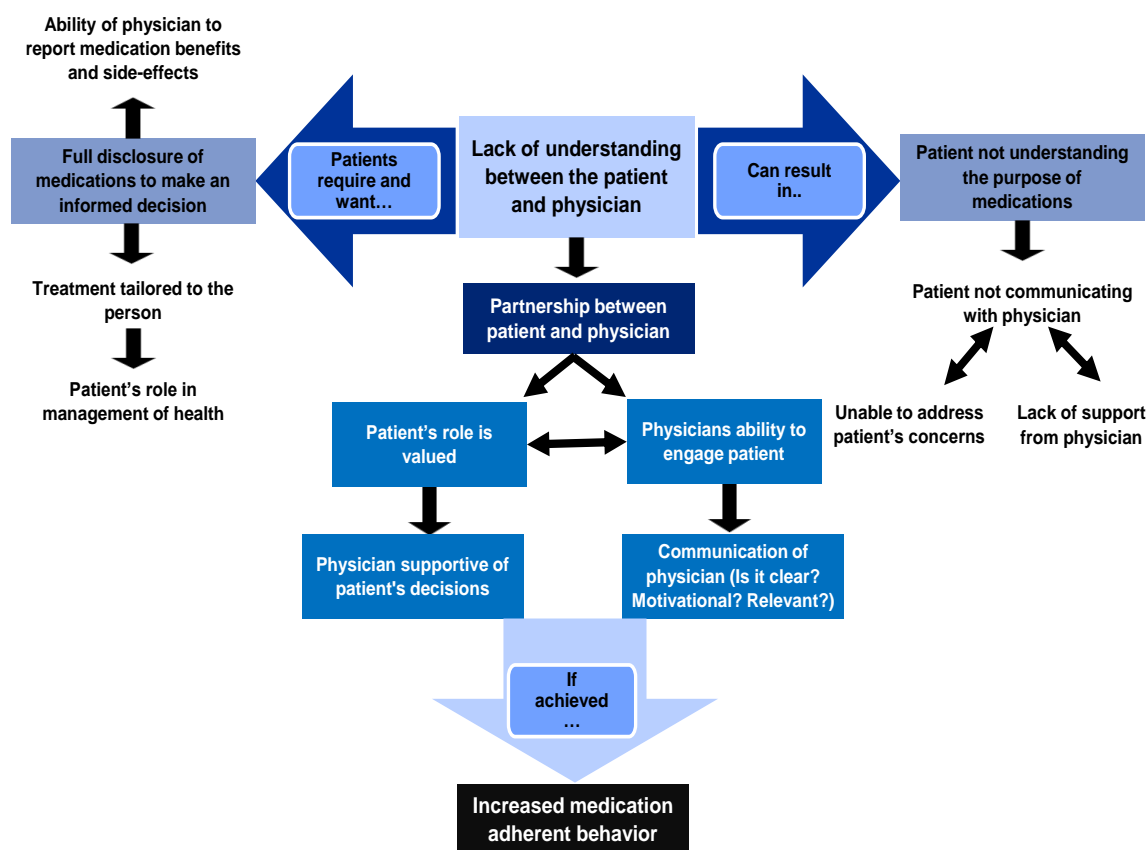
Patients whose physicians communicated poorly were at a 19% higher risk of non-adherence than patients whose physicians communicated well (Ledford *et al.*, 2010) and when appointments are often limited in time it is necessary for the physician to be able to communicate the importance of adherence (Wagner *et al.*, 2005). The effectiveness and perception of information may vary based on the physician's role in managing the patient's health. Patients may be more inclined to share information with their family physician versus a specialist he/she is required to see. Furthermore, access to varying health care providers was not the only barrier but access regarding the health care system was also a cited issue by patients. Audulv *et al.* (2012) found that some participants were accustomed to the health care system while others described how their limited knowledge of the health care system posed difficulties in accessing treatments. Patient-physician communication is extremely influential in determining the extent that patients adhere to a drug regimen and should be considered when developing effective health interventions.

*Understanding the person with the chronic condition(s):*

Through candid communication, the physician must tailor the treatment according to each patient while recognizing the values and beliefs of the patient. According to the chronic care model (CCM) there needs to be an understanding of the illness and the person, not just the disease, which is necessary if patient-centred care is going to be achieved (Kaufman & Birks, 2009; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). Unfortunately, most clinicians focus on disease-specific outcomes. However, patient priorities are more variable, specifically for those with multiple health conditions (Tinetti *et al.*, 2004). When physicians prescribe a medication it is primarily based on the

benefits of the medication(s) but patients will base a decision to start or continue a medication on the side-effects experienced, the time required for the medication to be effective, convenience, and cost (Tinetti *et al.*, 2004). Physicians must be able to recognize the basis of the patient's decisions and resolve the inherent tension of prescribing for the disease and prescribing for the patient. Refer to Figure 4 for a summary of what has been outlined in the literature in patient-physician communication (Audulv *et al.*, 2012; Charmaz, 1990; Golay, 2011; Kaufman & Birks, 2009; Law *et al.*, 2012; Nair *et al.*, 2002; Osterberg & Blaschke, 2005; Tinetti *et al.*, 2004; Townsend *et al.*, 2003; Wagner *et al.*, 2005).

**Figure 4. Patient-physician communication**



Furthermore, physicians need to take a holistic approach in understanding the patient as a whole, as previously exemplified individual factors impact a person's ability in adhering to a prescribed drug regimen (Auduly *et al.*, 2012; Charmaz, 1990; Golay, 2011; Law *et al.*, 2012; Osterberg & Blaschke, 2005; Townsend *et al.*, 2003). The physician should consider individual differences when determining the best method in presenting treatment options and in exemplifying the importance of the selected treatment; this can be reflected in the health care system's ability to properly train physicians to elicit patient's individual differences and then prescribe a treatment that is tailored to the individual. Those with chronic conditions exhibited better rates of adherence, if one knew the medication was prescribed for them 'personally', rather than a standard medication used for anyone with that condition (Nair *et al.*, 2002). Recognizing the patient as an individual will aid the physician in prescribing medications and should be considered by healthcare as whole not collectively among physicians.

Research has suggested that in order to improve medication adherence, it is essential that there be a realistic assessment of the patient's knowledge, an understanding of the patient's beliefs regarding treatment options, and communication needs to be clear, sensitive, and motivational when addressing barriers to medication (Kaufman & Birks, 2009; Kreps *et al.*, 2011; Svarstad *et al.*, 1999). Furthermore, overall better health outcomes have been found in patients who play an active role in the management of their health, in setting self-management goals with the aid of their physician, developing action plans, and are provided with support from their physician (Wagner *et al.*, 2005). To achieve improved health outcomes, certain variables must be considered by the physician. For example, the cost of medication needs to be considered by physicians,



specifically how this barrier varies based upon individual differences. Physicians need to ensure the patient understands the importance of taking a prescribed medication and the rationale behind the treatment. Physicians must be able to communicate the benefits of the medication(s) despite the associated risks and how the benefits outweigh the side-effects or risks associated with the prescribed treatment. However, despite the literature citing the importance of patient-physician communication it is still uncertain to what extent this impacts adherent behavior. Furthermore, there is minimal literature that has been able to exemplify how various relationships with numerous health care providers (i.e. family physician, specialists, and pharmacists) effect a patient's ability to follow a prescribed a drug regimen.

### **The Health Care System in Canada**

#### *Structural barriers:*

Canada's health care system has been cited as a barrier to medication adherence and it is not understood to what extent this barrier affects individual's choices to follow their physician's recommendations. Schoen *et al.* (2010) compared and contrasted the health care systems of 11 different countries, Canada being one of them. 3 302 Canadian participants were sampled and when adults were asked if they were able to see a doctor or nurse the same day care was desired, Canada was rated the lowest at 45% versus 93% of adults from Switzerland indicating that it was possible. When adults were asked if they had to wait more than 6 days to see a physician, Canada had the highest percentage at 33% compared to the United States where only 19% of adults had to wait more than 6 days to see a physician when care was needed. Finally, Canada had the highest percentage of 41% in having to wait more than 2 months to see a specialist versus

Australia where only 28% cited this as being an issue. This study exemplified that Canada's health care system was not easily accessible and may explain individual's hesitancy in wanting to seek health care. When individuals avoid seeing their physician because of long wait times, patient's decisions become limited due to increased severity and progression of their condition.

Ledford *et al.* (2010) conducted a study that included 30 participants who were diagnosed with various chronic conditions who were over and under the age of 50. The health care system posed a challenge to participants, specifically through difficulties in scheduling appointments, contacting their physician via telephone, and getting refills on prescriptions (Ledford *et al.*, 2010). However, Ledford *et al.* (2010) did not specify the mean age, the age range of participants, or the number of chronic conditions with which participants were diagnosed. As previously illustrated, age and the number of chronic conditions patients were diagnosed with, directly affected adherence and the impact of barriers varied based on individual factors. Specific variables within the health care system such as physician communication contributed to the patient's ability to adhere to a drug regimen.

#### *Treatment options:*

Interventions need to be implemented that attempt to re-structure the health care system by improving the availability of physicians and the physician's ability to communicate with patients. If this solution is not attainable, then patients should be provided with alternatives, such as the increased availability of nurse practitioners to address immediate concerns the patient has and the use of pharmacists to refill prescriptions and be a source of information. Kreps *et al.* (2011) and Nair *et al.* (2002)

concluded that although pharmacists were the most accessible source of information for patients, pharmacists are at a disadvantage in providing information to patients because they lack access to the diagnosis that engendered a prescription. If pharmacists are unable to provide patients with immediate and credible information, patients have no choice but to seek information from other less reliable sources. This may affect the patient's ability to make informed decisions regarding their health. By having the patient play an integral role in their own health and treatment, the patient may be more inclined to adhere to a drug regimen if the value of their role in improving their own health is clear.

Kaufman and Birks (2009) and Lewis *et al.* (2003) concluded that it is necessary to incorporate the patient's preferences and values into treatment decision making but the rationale behind a patient's treatment decisions is poorly understood. Research has emphasized the importance of patient-centred care, which is characterized by promoting a better understanding of the patient's life, empowering the patients, and tailoring treatment to the patient's needs and preferences (Golay, 2011; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). However, the literature has been unable to exemplify how or if patient-centred care improves adherence and the affect it has on a patient's decision making, specifically in those who are required to make decisions on a daily basis. Through the use of grounded theory it will provide insight into the meanings patients attach to their treatment decisions and how their decisions are constructed (Corbin & Strauss, 2008; Patton, 1980). There has been minimal literature to demonstrate how choices are made over time when individuals are dealing with a condition on a daily basis. However, it is still essential to evaluate medication adherence interventions and the strengths and pitfalls within the

interventions. This will aid in designing a framework for physicians in understanding what needs to be done to improve patient adherence.

### **Evaluation of Medication Adherence Interventions**

When reviewing the barriers that have prevented individuals from adhering to their medications, interventions need to be implemented that target a specific population while considering individual differences. It is important to develop interventions that increase adherence to prescribed medication to improve individual and public health (Golay, 2011; Kennedy & Morgan, 2006; Kreps *et al.*, 2011). However, there still is no direct link between effective interventions that result in improvements in clinical outcomes or the effect decision making has on adherence interventions (Golay, 2011; Kreps *et al.*, 2011; Ledford *et al.*, 2010; Zhao *et al.*, 2011). Interventions that have been deemed successful are typically complex and costly, yet there is no standardization in determining what is considered ‘adherent behaviour’ and thus, what classifies an intervention as successful. For example, some clinical trials consider treatment outcomes to be considered effective if adherence is greater than 80% versus other trials that require 95% adherence for the results to be significant and the intervention successful (McDonald *et al.*, 2002; Osterberg & Blaschke, 2005; Peterson *et al.*, 2003). If there is no standardization in determining the successfulness of interventions then it is challenging to determine if one intervention is more effective than another. However, interventions have been developed that specifically target the barriers that have been addressed by patients. Interventions utilized to improve medication adherence can be social and economical, healthcare oriented, therapy-related, and patient-related.

*Social and economical:*

When measuring medication adherence, it should be cost effective, easy to use in the clinical practice, relevant, informative, and non-invasive (Golay, 2011; Wagner *et al.*, 2005). However, no current intervention meets this criterion. Devising an intervention that is relevant is challenging since, as previously outlined, adherence varies based upon the individual factors. Interventions have been implemented that have attempted to address socio-economic factors associated with poor adherence. Physicians have been trained to offer tailored explanations about treatment options to address illiteracy while considering the patient's level of education (Golay, 2011; Svarstad *et al.*, 1999; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). However, this is assuming that the physician is able to make appropriate conclusions about the patient's level of education. As previously cited patient-physician communication is a common barrier to medication adherence, questioning the effectiveness of using tailored communication as a means to improve adherence.

Medical social workers have been provided to families who cite unemployment and unstable living conditions as a barrier (Golay, 2011). By providing families with help, patients and their families are able to have access to social security, housing and other benefits (Golay, 2011). Furthermore, social support has been associated with improved medication adherence. Interventions have been developed that focused on the use of patient groups that allowed individuals to speak with others who experienced similar hardships (Auduly *et al.*, 2012; Golay, 2011; Kaufman & Birks, 2009). These interventions also served as an additional method for patients to discover other self-management strategies (Auduly *et al.*, 2012; Golay, 2011; Kaufman & Birks, 2009;

O'Neil & Morrow, 2001; Pittman, 1999). Patient groups may help to improve knowledge and address social isolation, especially if the condition is rare. However, when reviewing the interventions that have been implemented to address socio-economic factors, none of the interventions quantified the costs and consequences associated with the various methods utilized to improve adherence. Furthermore, there was no assessment of reliability or validity in determining what interventions were effective or if there were any clinical outcomes associated with the interventions. If socio-economic factors are the focal point for interventions, then cost and accessibility needs to be further considered to target the population that is primarily affected by this barrier.

*Health care – oriented:*

To improve medication adherence, it is important to evaluate interventions that focus on one of the most crucial aspects of medication adherence – the health care system. Research has demonstrated that adherence has improved based on the communication between the patient and the healthcare professional (Kreps *et al.*, 2011; Ledford *et al.*, 2010; Lewis *et al.*, 2003; Pittman, 1999; Wagner *et al.*, 2005; Zhao *et al.*, 2011); a meta-analysis of 48 studies found a statistically significant correlation between improved patient-physician communication and better medication adherence in those with a chronic condition (Gold & McClung, 2006). Relationships between health care professionals and the patient should be built upon trust to facilitate open communication and engender a patient's confidence in the professional's recommendations (Golay, 2011; Ledford *et al.*, 2010; Osterberg & Blaschke, 2005; Wagner *et al.*, 2005). Interventions have been developed that have provided health care professionals with high-quality training on how to educate patients about diseases and available treatments (Golay, 2011;

Kaufman & Birks, 2009; Svarstad *et al.*, 1999). Physicians were also trained on how to elicit the patient's perspectives since patients were more likely to adhere to a drug regimen if one played a role in the treatment decision (Golay, 2011; Ledford *et al.*, 2010; Lewis *et al.*, 2003; Wagner *et al.*, 2005). This process is referred to as 'patient centered care' (PCC), which responds to the information needs and desires of the patient (Ledford *et al.*, 2010; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). PCC was associated with higher levels of patient perceived satisfaction and has resulted in overall improved health outcomes (Ledford *et al.*, 2010). When evaluating PCC, Ledford *et al.* (2010) did not outline clinical outcomes. Therefore, the results were not transferable, since the improved health outcomes and the beneficiaries were not specified.

Furthermore, Wagner *et al.* (2005) found that interventions that have been designed that encourage greater patient involvement have increased patient satisfaction and may positively impact health behaviours. Yet the findings were mixed and it could not be concluded how effective PCC was. Brehaut *et al.* (2003) also found that interventions designed to increase patient involvement have many benefits for patients, including greater confidence in treatment decisions, improved knowledge, more realistic expectations of the health outcomes, clarification of personal values, and improved feelings of support. However, an issue with patient-centred interventions is if a poor health outcome occurs causing the patient to regret their decision; the patient will play a less active role in future treatment decisions and will be less likely to adhere to their medications because of their minimal involvement in their treatment choices (Brehaut *et al.*, 2003).

Interventions have also been implemented that have focused on re-structuring the health care system. Systems have been developed to aid in reminding patients of their appointments specifically through the use of telephone and letter reminders, referred to as 'cue-dose training' (Golay, 2011; Osterberg & Blaschke, 2005; Tinetti *et al.*, 2004). Furthermore, clinics have re-structured the hours of operation, providing the option of evening appointments which has resulted in shorter wait times (Golay, 2011; Osterberg & Blaschke, 2005). For example, clinical attendance rates and medication adherence improved in young adults with type 1 diabetes that had the option of evening appointments and were reminded of scheduled appointments via telephone, versus clinics that had conventional hours and did not proactively remind patients about appointments (Wills *et al.*, 2003). However, cost effectiveness was not considered for any of these initiatives and may not be feasible for clinics that do not have the resources to provide evening appointments or scheduled reminders; despite the proof that these factors improve medication adherence.

Finally, certain interventions have focused on using a multidisciplinary approach involving pharmacists, nurse practitioners, and physicians as a means to improve medication adherence. Research has demonstrated that community pharmacists can help improve adherence by identifying non-adherent behaviors amongst patients and aid in implementing solutions (Nair *et al.*, 2002; Raynor *et al.*, 2000). Non-adherent behaviours can be determined by reviewing pharmacy refill records and drug claims, which is an objective and inexpensive method of measuring adherence over an extended period of time (Svarstad *et al.*, 1999). Interventions have been implemented that have focused on the use of therapy management services for those with chronic conditions (i.e. offering



appointments to discuss therapy, offering personalized packaging, finding a peer sponsor, and regular telephone calls), which has resulted in improved adherence. However, further research needs to be done in utilizing a multidisciplinary approach instead of focusing on each factor individually or claiming to use a multidisciplinary approach when this is not taking place. For example, this approach should question: how can physicians communicate with community pharmacists in improving adherence amongst patients who clearly exemplify non-adherent behavior? If physicians are unable to elicit the patient's perspectives regarding treatment options, can a nurse practitioner be expected to do so? Each member of a multidisciplinary team will be able to offer solutions that could be effective if done individually however if health care professionals are able to work collectively together, medication adherence interventions may be more successful in catering to the patient's needs and understanding the rationale of a lay person's choices.

*Therapy – related:*

The primary objective of therapy-related interventions is to modify the patient's drug regimen according to their lifestyle. However, this can only be achieved if patients are able to recognize that the treatment benefits outweigh the costs and adverse effects of the selected treatment. Systems have been developed that have been aimed at reducing medication frequency while integrating medication schedules with the individual's lifestyle (Golay, 2011; Peterson *et al.*, 2003; Wang *et al.*, 2011). A systematic review of 20 studies found that all trials reported higher medication adherence (based on electronic monitoring) with lower dosing frequency regimens (Kaufman & Birks, 2009; Saini, Schoenfeld, Kaulback, & Dubinsky, 2009; Wang *et al.*, 2011). Patients who were receiving once-daily regimens were 22% to 41% more adherent than those taking

medications three times a day and 2% to 44% more likely to adhere than those using twice-daily regimens (Saini *et al.*, 2009). However, this may not be a reliable comparison based on the large range between the percentages in determining adherent behaviour. Yet there was still improvement in adherence illustrating that by altering dose schedules it may be an effective intervention.

Wang *et al.* (2011) formulated an intervention which focused on altering dose schedule that were 'less rigid' and coincided with daily times (8:00 a.m., 12:00 p.m., 6:00 p.m., and 10:00 p.m.); with some fluctuations, give or take an hour. There was an improvement in medication adherence, however the results did not outline to what extent adherent behavior was exhibited or the characteristics of the sample involved in the study; as previously exemplified, adherent behaviour can vary based on individual factors especially for those who are diagnosed with a chronic versus an acute condition. Furthermore, the objective of the intervention was to provide a 'less rigid' schedule yet times were predetermined indicating when medication should be taken. If patients are being told when to take their medications, then their individual lifestyle is not being considered. McDonald *et al.* (2002) conducted a scientific review and concluded that when considering interventions for those with chronic conditions, implementing changes to dose schedules was relatively simple, convenient, cost-effective, and has been somewhat effective in improving medication adherence. Research has been able to exemplify improvements in adherent behavior by modifying the patient's drug regimen. However, further research needs to investigate the use of low dose frequency regimens that can produce significant clinical outcomes while evaluating patient decision making.

*Patient – related:*

When developing interventions that are focused directly on the patient, there needs to be an emphasis on formulating treatment options that patients feel they have some control over and want to implement (Asbring, 2001; Charmaz, 1994; Kaufman & Birks, 2009; Kralik, 2002). Patients need to feel a sense of control over something since those with a chronic condition can only control their condition to a point. Interventions have been implemented that focus on improving dose schedules by using pill boxes to organize doses (Dosette boxes), simplifying the regimen to daily doses, and cues provided to remind patients to take their medications (Golay, 2011; Osterberg & Blaschke, 2005; Peterson *et al.*, 2003; Tinetti *et al.*, 2004). In combination with this the physician should address any lay beliefs about the disease(s) and provide the patient with education on the pathology and the importance of treatment. Also, periodic monitoring and reinforcement should be consistently conducted to help patients in overcoming intentional and unintentional poor adherence (Golay, 2011; Osterberg & Blaschke, 2005; Tinetti *et al.*, 2004). The framework of a patient-oriented intervention was reviewed by Golay (2011) and Osterberg and Blaschke (2005); however, the effectiveness of the intervention or who the intervention was specifically targeting was never outlined.

Interventions have also been implemented that focused on helping patients recognize non-adherent behaviour, which was measured through the use of pill counting and patient diaries. Pill counting and patient diaries are relatively straightforward to use in measuring adherence, are inexpensive and convenient, but are extremely subjective (Golay, 2011; Osterberg & Blaschke, 2005; Svarstad *et al.*, 1999). Pill dumping and patient diaries can produce misleading results due to patients' under-reporting non-

adherence (Golay, 2011; Osterberg & Blaschke, 2005; Svarstad *et al.*, 1999). However, to counter the issue of pill counting, Medication Events Monitoring System (MEMS) was developed as an innovative method to monitor non-adherence. MEMS is a microprocessor that records the date and time of each bottle opening, with each opening counting as a dosage (Golay, 2011; Svarstad *et al.*, 1999). This tool may be effective in improving medication adherence but may benefit the patient more if used in combination with a self-reported measure such as patient diaries since patients can dispose of the tablet with the device still measuring that the medication was taken. There have been no interventions implemented that have focused on the use of MEMS to improve medication adherence in those with chronic conditions between the ages of 40 to 55 who are required to take more than three medications. However, research may benefit by investigating the use of this tool with other subjective measures.

When creating interventions, there are numerous options that can be the focal point in ensuring medication adherence. By using a socio-economic approach, additional resources such as the use of a medical social worker and social assistance are provided to the patient to aid in adhering to their drug regimen. Furthermore, interventions could focus solely on re-structuring the healthcare system and provide physicians with training that emphasizes the importance of PCC. If patients are required to take multiple medications, the use of low dose frequency schedules may improve adherence. Patients are not always aware of non-adherence and this behavior can be unintentional. The implementation of devices (i.e. pill counting, MEMS, Dosette boxes, calendar packs, patient diaries, etc.) will help the patient in recognizing when medication is not being taken and when it should be taken. However, when reviewing the various approaches to

medication adherence interventions, it is evident that no approach clearly produced clinical outcomes or exemplified how patients are making choices to adhere to their drug regimen. Many of the strategies outlined that adherent behavior was improved but never to what extent or who specifically exemplified this behavior. This demonstrates the gaps in current research and the importance of developing a process-evaluation plan that considers each step of the intervention needed to evaluate the experiences of individuals diagnosed with a chronic condition (Charmaz, 1990). This justifies the importance of evaluating the choices made by individuals between the ages of 40 to 55 who are prescribed more than 3 medications. The literature available has been unable to provide a rationale of the decisions a lay person is making pertaining to their health.

### **Chapter 3: Methods**

#### **Theoretical Framework:**

According to Corbin and Strauss (2008) theoretical frameworks are essential in providing a justification for research and serve as a guide throughout the research process. The purpose of this research is to provide health care providers with a framework to aid in understanding how patient's decisions are made in medication adherence, the rationale behind these decisions, and the meanings patients associate with these decisions. Symbolic interactionism is a theoretical framework that best supports this purpose.

Symbolic interactionism is 'the study of human beings interacting symbolically with each other and with themselves, and in the process of that symbolic interaction it involves making decisions and directing their streams of action' (Charon, 1989, p.140). There is not a focus solely on individuals interacting but also what is happening within

the person – the person acts according to a world he/she defines, which is influenced by the interaction with others and how one defines themselves (Charon, 1989; Soloski & Daley, 1978). However, there is a constant, variable interaction between the self and others.

‘Altercasting’ involves casting people into a role that ‘we’ want so that the person starts to think of themselves in that manner and behave in that way (Charon, 1989).

Previous literature has exemplified how individuals who are diagnosed with a chronic condition struggle with their identity and over-compensate in roles previously held to avoid being labelled as ‘ill’ (Asbring, 2001; Auduly *et al.*, 2012; Charmaz, 1994; Kralik, 2002; Townsend *et al.*, 2003). This may be explained through the concept of

‘presentation of self to others’, which outlines that one acts around others according to the identity he/she has claimed and chooses to represent to others (Charon, 1989). Not only is the person labelling themselves but is assuming that others are labelling them.

Thus, this influences what ones does and how one acts. By considering ‘altercasting’ and ‘presentation of self to others’, it may provide insight during data analysis in rationalizing how medication choices are being made and the direct effects of healthcare decisions on self-identity.

A key tenet of this theoretical framework is humans purposely act towards objects/others by the meanings associated with it and human acts are intended to communicate a message (Charon, 1989; Schou & Hewison, 1998; Soloski & Daley, 1978). The acts people communicate become symbols and in turn other’s actions are interpreted and viewed as intentional communication, which becomes a ‘significant gesture’ (Charon, 1989). Meaning to the person then becomes generated based upon the

social interaction with others (Schou & Hewison, 1998). This is necessary to consider in relation to how patients choose to base decisions according to their physician's recommendations. By not adhering to one's drug regime, a message is being communicated to the physician. However, it is not understood the basis of this message especially if adherence to other medications are taking place.

A symbolic interactionist perspective suggests that humans focus on what is relevant and useful directly for that person; 'perspectives, facts, definitions, and ideas are all judged by the individual in terms of applicability' (Charon, 1989, p.27). If the communication aids the person in achieving their goals, then the information is applied (Charon, 1989; Soloski & Daley, 1978). However, if it is not applicable then one will choose to alter the information or will choose to forget (Charon, 1989; Soloski & Daley, 1978). This then impacts the meaning individuals construct. The meanings of objects vary according to the person and the purpose of the object determines the object's meaning (Charon, 1989; Holstein & Gubrium, 2003). When considering medication adherence, it has been previously outlined that a lay person will associate different meanings to their drug regimen (Audulv *et al.*, 2012; Charmaz, 1994; Kralik, 2002; Townsend *et al.*, 2003). A drug regimen to some may be viewed as necessary in an effort to achieve normality or to retain one's previous identity. Others may view their drug regime as controlling or demanding and choose not to adhere to their physician's recommendations. Thus, the meaning behind adhering to one's prescribed medications alters according to the person.

Symbolic interactionism considers how multi-faceted people are and recognizes that decision-making is a continual process that is impacted by the interaction with

others, objects, and one's self-identity. This aligns with this research project, which aims to further understand the decision-making process patients are making regarding their personal health. Also, the objective of this research study is to provide health care professionals with a better understanding of a patient's decision in adhering to his/her prescribed drug regimen.

### **Epistemological/ Paradigmatic Perspective:**

When considering what methodology to utilize it is important to situate oneself within a worldview, which will affect one's epistemological perspective. Epistemology is 'the study of nature of knowledge and justification' (Carter & Little, 2007, p.1317). Objectivism refers to reliable, checked, and controlled knowledge that is not distorted by personal bias or prejudice (Kvale & Brinkman, 2009). The researcher and researched are independent from each other, with the ideal being that neither have an influence on the research process (Alvesson & Deetz, 2000). Traditionally grounded theory, which will be the methodology utilized within this research, has been based upon objectivity (Denzin & Lincoln, 2011). However, it would not be realistic to situate the researcher or the objectives under study within this epistemological perspective. The researcher is not searching for a single, external truth and more importantly those involved within this study would not be viewed as "researched" but participants, recognizing that there is no relational hierarchy. Therefore, the epistemological view would be within subjectivism.

Knowledge is created within subjectivism through the interaction between the researcher and the participants (Alvesson & Deetz, 2000; Holstein & Gubrium, 2008). The researcher is connected to participants and creates the findings as the research process proceeds (Alvesson & Deetz, 2000; Holstein & Gubrium, 2008). Subjectivity is



utilized as a pathway to deeply understand the human dimensions of the world in general as well as the phenomenon being examined (Patton, 2002). Furthermore, the methodology serving as a basis for this project, constructivist grounded theory, recognizes the researcher's role and the focus shifts away from the traditional grounded theory roots of objectivity and positivist to subjectivism and relativism (Denzin & Lincoln, 2011; Holstein & Gubrium, 2008). The purpose of using constructivist grounded theory is to provide an increased understanding of the social structures within the health care industry and this can only be done through individual's subjective experiences (Denzin & Lincoln, 2011).

It is vital that subjectivity serve as a basis throughout this research project since it is concerned with multiple truths that will be individualistic. In order to gain rich descriptions, participants must be able to recognize the researcher as someone he/she can trust and share their personal experiences with. By situating oneself within subjectivism it will reshape the interaction between the researcher and the participant; meaning will be co-constructed instead of focused solely on the participant (Mills, Bonner, & Francis, 2006). Given that the researcher will be maintaining a subjectivist perspective it seems appropriate that the worldview be situated within the context of the interpretative paradigm.

A paradigm is a perspective that aids in drawing out contextual factors and identifying relationships between context and process (Corbin & Strauss, 2008). The core belief of interpretivism is the reality that we know is socially constructed (Esterberg, 2002; Gilboe, Campbell, & Berman, 1995; Willis, 2007). The method the researcher will be utilizing (semi-structured interviews) relies on individual's lived experiences and how

participants socially construct these experiences in relation to medication use. Semi-structured interviews are the best data collection method to use within this paradigm, since it seeks input from participants to create a representation of the individual's reality (Gilboe *et al.*, 1995). What individuals say will determine the depth, richness, and authenticity of the research results.

The purpose of conducting research within this paradigm is to look for an understanding of a particular context (Willis, 2007). There is no search for universal laws or rules (Willis, 2007). This paradigm allows for flexibility and theory development, which is dependent on the researcher's views and learning about the worlds of others (Creswell, Hanson, Clark, & Morales, 2007; Wuest, 2011). This is also exemplified within the research methodology, constructivist grounded theory, which will be outlined in greater detail later.

Interpretivism is based upon rationalism and relativism and since constructivist grounded theory will be used, which is concerned with the complexities of particular worlds, views, and actions (Creswell *et al.*, 2011), it is beneficial to consider relativism in further detail. Relativism is the reality that one perceives is conditioned by one's own experiences and culture (Willis, 2007). This is further influenced by anti-foundationalism, which outlines that there is no secure foundation that humans can use to decide what is true and what is not (Willis, 2007). This view of recognizing that there is no divine truth but that reality is shaped by experiences will serve as a basis during the analysis phase of my data collection. An interpretative and subjective perspective will serve as a basis for this research project and provide further reasoning for selecting constructivist ground theory as the methodology.

### **Methodology:**

According to Creswell *et al.* (2007) and Moustakes (1994), grounded theory is used to generate an explanation or theory of a process, action, or interaction that is created through the voices of individuals. Theory construction is based upon issues that are relevant to people's lives and generated through the process of inductive research (Charmaz, 1995; Corbin & Strauss, 2008; Denzin & Lincoln, 2011; Mills *et al.*, 2006; Patton, 1980). Since the focus is on people's individual experiences, grounded theory acknowledges multiple realities and truths. The methodology is consistent with an interpretive worldview – the interpretations must include the perspectives and voices of the individuals being studied while recognizing the researcher's role (Mills *et al.*, 2006; Wuest, 2011). The purpose of this research project is to provide a better conceptual understanding of the decision-making process for individuals who are required to take multiple medications. Thus, it is important that participant's views and voices become an integral part of the research process, which is why constructivist grounded theory will be an appropriate methodology to utilize.

Constructivist grounded theory focuses on the context, positions, discourses, meanings, and actions (Denzin & Lincoln, 2011). The purpose is to learn how situations are defined and how power, oppression, and inequities affect individuals (Denzin & Lincoln, 2011). Participants reconstruct their personal experiences and experiences are then used to show the complexities of particular worlds, views, and actions, which are rendered into theoretical interpretations (Creswell *et al.*, 2007; Mills *et al.*, 2006; Schou & Hewison, 1998). As previously exemplified within the literature, medication adherence interventions have failed to recognize individual experiences (Britten, 2003;

Kreps *et al.*, 2011; McDonald *et al.*, 2002), which are extremely complex when considering the barriers that have been recognized in preventing patients from adhering to their prescribed drug regimen. A constructivist approach assumes that reality is multiple and constructed under specific conditions (Creswell *et al.*, 2007; Holstein & Gubrium, 2008). By using this approach as a guide each participant's social constructions will be outlined with the intention of presenting emerging themes based upon the co-construction of meaning between the researcher and the participants.

Schou and Hewison (1998) outlined the importance of using constructivist grounded theory with chronic conditions. By using grounded theory, the focus shifts away from the pathology and coping strategies when reviewing patient's health accounts to instead a focus on self-stories and an exploration of experiences containing many and sometime contradictory voices (Schou & Hewison, 1998). The literature has outlined the complications individuals with a chronic condition face, including the ability of one to accept their condition while finding a balance between the challenges with their health and their self (Asbring, 2001; Charmaz, 1994; Kralik, 2002; Tinetti *et al.*, 2004). This methodology recognizes that medication forces people to account for their condition and the handling of it in daily life and to legitimize one's decisions to avoid societal backlash (Schou & Hewison, 1998). Participants may have that commonality of being diagnosed with a chronic condition yet there may be differences in their experiences with living with a chronic condition. This is why it is important when constructing interpretations to locate it within the participant's experience (Schou & Hewison, 1998). A constructivism approach to grounded theory makes the assumption that human beings each have their own diverse world that is shaped by the person's views, beliefs, feelings, assumptions,

and ideologies (Creswell *et al.*, 2007), which is consistent with this research project in recognizing each participant individually.

The purpose of using a constructivist grounded theory approach for this study was for several reasons. This specific approach accounts for variations in behaviors (Wuest, 2011). This is necessary to consider if a patient's individual experiences are going to be used to formulate a theory or framework for health care providers in understanding the decision-making process of a patient. Furthermore, it will assist health care professionals in conceptualizing what is significant to the person and the ways that social and structural conditions influence how people manage their lives (Patton, 1980; Wuest, 2011). Kathy Charmaz (1995) outlined that constructivism grounded theory is most suitable 'for studying individual process, interpersonal relations, and the reciprocal effects between individuals and larger social processes' (p.96). Finally, this is an ideal methodology to use to generate a theoretical framework that could change individual practices, alter procedures, and shift policies (Patton, 1980; Wuest, 2011). Thus, it is ideal to implement constructivist grounded theory if this purpose of the research is to be achieved.

### **Interviews:**

If a framework is going to be developed that will aid health care professionals in understanding a patient's decision-making process then patients must be able to speak directly of these experiences. Schou and Hewsison (1998) emphasized the importance of using a method that allowed the researcher to hear participant's social accounts and view the person as a member of a social world who could contribute to changes in practices within the healthcare industry. In order for participant's voices to be heard, semi-structured interviews are an ideal method.

By using constructivist grounded theory as the methodology, interviews are an ideal choice because interviews explore and examine participant's concerns. This also gives the researcher control to continually develop and modify questions around these concerns, subsequently speaking to the participant's experiences (Creswell *et al.*, 2007; Holstein & Gubrium, 2003). Holstein and Gubrium (2003) further outlined the importance of using in-depth interviewing with constructivist grounded theory because the interviewee has more direct control over the construction of the data compared to other methods such as ethnography or textual analysis.

Control of the data is a key variant of constructivist grounded theory but the participant's experience must prevail. The researcher must enter the interested phenomenon and work together with the participant to co-construct the data through interaction, which is best achieved through multiple, in-depth interviews (Denzin & Lincoln, 2011; Mills *et al.*, 2006). Therefore, the researcher should conduct multiple interviews when using a constructivist grounded theory approach since the interviewer may have to go back to the participant and ask additional questions to provide further theoretical insight (Holstein & Gubrium, 2003). New questions are developed to provide insights that may have been missed during previous interviews and strengthen emerging themes within the data (Holstein & Gubrium, 2003). However, based on time and financial constraints, one interview was conducted with participants.

To guarantee that certain subject areas will be examined (i.e. specific barriers that have prevented patients from adhering to their prescribed drug regimen), an interview guide was used to allow for greater flexibility during the interview (refer to Appendix A). The interview guide was developed based on common questions exemplified in the

literature, specifically using the methodology of constructivist grounded theory while interviewing individuals who had a chronic condition. Moreover, the interview guide was also piloted tested with five individuals, which resulted in alterations to the interview guide to allow individuals to speak more to the decisions they have made regarding their medication as well as an opportunity to develop comfort and trust with the lead researcher through the inclusion of icebreaker questions. The interview guide was not only piloted on five individuals yet was reviewed numerous times by the researcher before each interview to ensure questions were consistent as participants were only interviewed at one point in time. As interviews progressed, the order of questions were altered as well as questions were erased that resulted in repetition of responses. Based on the researcher's experience it became apparent that individuals concluded they were on medication based on certain experiences; thus, there was a focus on participants' experiences related to them first being prescribed their medications. As Patton (2002) outlined, an interview guide serves as a basic checklist to ensure all relevant issues are covered and the same basic lines of inquiry are pursued with each participants. This was the focus for the researcher as questions were never worded exactly the same yet there were common themes asked of each participant.

### **Data Collection Procedures**

#### *Sampling strategy:*

Purposive sampling was used to recruit participants to gather information rich cases. According to Carter and Little (2007), Esterberg (2002) and Patton (2002), purposive sampling is seeking rich experiences of a phenomenon of interest and is targeting a certain group with specific characteristics. By using this sampling strategy, it

will provide an in-depth understanding of a specific phenomenon rather than result in empirical generalizations (Patton, 2002). Theoretical sampling is typically used in accordance with grounded theory. This form of sampling does not take place at a single point in the inquiry process but is a recurrent feature and at various times the researcher must go back to participants to collect more information around settings, events, and people (Hammersley, 2006). However, by using a constructivist approach it does not require the researcher to follow certain guidelines or stringencies that are utilized in grounded theory such as theoretical sampling (Holstein & Gubrium, 2008). Furthermore, theoretical sampling was not possible within the context of this research study as participants were interviewed at one point in time.

*Sampling recruiting procedures:*

Participants were recruited through various methods within the Niagara and Halton region. Participants were recruited through referrals from a primary care office in Niagara, through Niagara Region Public Health, a physiotherapist office based out of Halton, and finally by the researcher through word of mouth.

All participants in some capacity were provided with a summary of the research project (refer to Appendix C) and if interested the researcher's contact information. This led to participants contacting the researcher via telephone or email expressing further interest in the project. The first conversation involved the researcher introducing the project, their background, and if the person met the sampling criteria (refer to Appendix D). All participants agreed to participate during the first conversation. If the person met the criteria, a letter of invitation (refer to Appendix E) was sent to the potential participants via email or provided before interviews began, which allowed the participant



to understand their rights as a participant, the purpose of the project, the implications of the project, and the requirements of participation. Once this was reviewed, the potential participants agreed to participate either through email or telephone and a location and interview time was determined that met the needs of the participants.

Although each participant agreed to participate by signing an informed consent form (refer to Appendix F), they were verbally reminded that for whatever reason if they chose not to participate, to notify the researcher in advance of the interview time. This affirmed their rights as a participant and respecting their choice to participate.

*Sample:*

The researcher recruited 15 participants who met the sampling criteria. This included: individuals between the ages of 40 to 55, currently taking three or more prescribed medications, and diagnosed with a chronic condition. The recruitment of these participants followed the sampling criteria procedures as outlined above. Table 1 outlines the characteristics of the sample population including additional information such as their occupation and their employment status since based on analysis this appeared to affect one's health condition.

**Table 1. Participant Bios**

Pseudonym	Case #	Gender	Diagnosis	# of medications	Occupation/employment status
Abby	1	F	High blood pressure High cholesterol Type 2 diabetes Gastro-reflex Depression	5	Office administrator (full-time)
Monica	2	F	Arthritis (multi-joint) Neuropathy Partial paralysis	9	Swimwear designer (part-time)
Liz	3	F	Type 2 diabetes Depression Anxiety	7	Nurse (full-time)

James	4	M	Type 2 diabetes	3	Customer representative (full-time)
Nicole	5	F	Hypothyroidism Type 2 diabetes Hypertension	5	Coordinator (full-time)
Galen	6	F	Rheumatoid arthritis Osteoporosis Anxiety	9	Office administrator (part-time)
Lauren	7	F	Type 2 diabetes High blood pressure	4	Family home visitor (part-time)
Krista	8	F	SI joint inverted Lower back pain Menopause	3	Previous personal support worker (unemployed)
Faye	9	F	Osteoarthritis Bipolar disorder Depression High cholesterol	4	House wife (unemployed)
Mikaela	10	F	Reactive arthritis Anxiety	6	Counts receivable clerk (full-time)
David	11	M	Type 2 diabetes Depression	3	Technologist (full-time)
Simon	12	M	Parkinson's disease Crohn's disease	>3	Pro athlete (semi-retired)
Julie	13	F	History of heart attacks Epilepsy Menopause	9	Home visitor (part-time)
Peter	14	M	Type 2 diabetes Diasyphlic epilepsy	6	Sales (self-employed)
Kelly	15	F	Thyroid disease Osteoporosis Acid reflex Type 2 diabetes High cholesterol	5	Restaurant owner (full-time)

### *Ethics:*

The researcher reviewed in detail the Tri – Council Statement: Ethical Conduct for Research Involving Humans and conformed to these guidelines. The researcher completed and submitted an application for ethical review of research involving human participants to Brock University's Research Ethics Board (REB) and was granted clearance on March 30, 2013 (12-176-COSBY). All REB protocols were followed to ensure confidentiality of the potential participants – all personal identifiers were removed

from the data and all identifying information was only known by the primary researcher. Numbers and pseudonyms were associated with each participant to ensure there were no linkages between the participant identifiers and interview data. Pseudonyms were used if names were outlined within the data. Participants were informed from the first conversation to when the interview took place that all involvement was strictly voluntary and participants had the right to refuse participation at any time. Before the interview took place this was also outlined in detail in the informed consent form.

*Data analysis:*

According to Mills, Bonner, and Francis (2006) when using constructivist grounded theory the first step before analysis has taken place is conducting an extensive literature review. The researcher conducted a literature review before data collection began, which was extremely beneficial because there was a heightened awareness about what participants could discuss during the interviews and prepared the researcher for what participants may be sharing about their experiences living with often multiple chronic conditions. The literature review also aided in determining questions to include as part of the interview guide to ensure there was a focus on participants' experiences and best methods in asking questions regarding medication adherence or non-adherence in those with a chronic condition. This was essential as based on time constraints, only one interview was conducted with participants and the researcher had to ensure that the appropriate questions were being asked and develop a rapport with participants in a short period of time.

Once a literature review is completed, recommended next steps for data analysis utilizing the methodology of constructivist grounded theory, include: line by line coding,

focused coding, moving codes to concepts, moving concepts to categories, researcher engages in memo-writing, the analysis is built directly on the researcher's interpretations of the data, and the analysis is compared to the literature (Charmaz, 1990; Charmaz, 1995; Mills *et al.*, 2006). Transcripts were analyzed in chronological order with respect to the order the interviews were conducted and data collection and analysis occurred simultaneously to inform each other (Hesse-Biber & Leavy, 2008).

The first step of data analysis involved line by line coding. The researcher defined the actions and events based on the words of participants (Charmaz, 1995; Denzin & Lincoln, 2011; Hesse-Biber & Leavy, 2008). By using words directly from the interviews, this aided the researcher in distancing herself from participants' experiences to maintain the authenticity of what the participant was saying. This step helped to refrain from putting the researcher's own motives and inputs into the collected data (Charmaz, 1995). By going through the interviews in detail, the researcher started to build insight which helped to determine the data that still needed to be collected (Charmaz, 1995). After coding the first transcript, the researcher went back to the interview guide and added areas to further pursue and deleted questions that did not add value to the overall project, with the intention of collecting data that was missed during the initial interviews (Charmaz, 1995; Creswell *et al.*, 2007; Holstein & Gubrium, 2003). Finally, line by line coding allowed the researcher to go deeper into the phenomena and explicate the data; it gave the researcher the opportunity to interact with the data and gave direction on areas to pursue (Denzin & Lincoln, 2011; Hesse-Biber & Leavy, 2008).

The second step was very similar to the first step but coding became more focused. The researcher took earlier codes that were reappearing and organized these

codes into larger pieces of data (Charmaz, 1995). This allowed the researcher to determine what codes made the most analytical sense and led to concepts and eventually categorizing the data (Charmaz, 1995). It should be noted that during this time, the researcher was very self-aware about why the data was being collected and realized that every participant had their own constructions of their health experiences despite all living with similar chronic conditions. The researcher throughout the process respected each participant's voice and looked at each transcript as if it had never been seen before.

Through line by line coding and focused coding, the researcher analyzed predominant codes and raised the codes to concept. By raising a code to a concept a label was applied to certain data (Charmaz, 1995). This step allowed the researcher to better organize the data instead of having long quotes of codes, key words were selected that kept prevailing in the stories of participants and made it more manageable when analyzing the data.

One of the most important steps was determining the categories. Based on the researcher's concepts, categories emerged in the data that were based on participants' voices (Mills *et al.*, 2006). Categories were labelled with simple, direct, and vivid words to ensure the researcher knew exactly what the category meant. To generate categories, the researcher compared participants who were diagnosed with similar conditions, compared the variations among all participants, compared data from the same individuals with themselves at different points in time, and finally the researcher considered individual's experiences to what was said in the literature. Categories were saturated by finding repeated evidence that supported the importance of moving a concept to a category (Charmaz, 1995).

During this step of the analysis, the researcher engaged in memo-writing. The researcher would re-read transcripts over and over again while documenting her own ideas and thoughts. This exercise was an integral part of the process because the researcher was able to organize the data easier, clarify what categories were major and what were minor, and captured what the researcher was thinking when reading participants' personal accounts (Charmaz, 1990; Charmaz, 1995; Hesse-Biber & Leavy, 2008). The researcher was given the opportunity to elaborate on certain codes and this became a tool for engaging in on-going dialog with self (Charmaz, 1990). Through memo-writing it created a heightened sense of awareness of predominant codes. As data analysis progressed, the researcher went back to initial interviews and re-coded the data because at the time the researcher did not realize the importance in what the participant was sharing until the researcher heard similar accounts from others. By writing memos it aided the researcher in examining one's own thoughts that emerged with the data (Hesse-Biber & Leavy, 2008; Starks & Trinidad, 2007). This served as an 'audit trail' whereby the researcher reflected on emerging thoughts throughout the data, how it related to one another, and how engaging with the data shaped one's understanding of the initial hypothesis (Starks & Trinidad, 2007). Thus, clarity was established in what the participant was saying and the perceptions of the researcher.

Finally, during the analysis stage the researcher interpreted the data and presented detailed interview quotes. By using data based on lived experiences, the researcher attended to how they constructed their own worlds (Charmaz, 1990; Charmaz, 1995). The researcher became immersed in the data and had a voice within the analysis but ensured the participant's accounts were visible, so there was a connection between

the analytical findings and the data from which they were derived from (Charmaz, 1995; Mills *et al.*, 2006). Once the analysis was completed it was compared extensively to the literature. This affirmed in some instances categories that were essential to include and also confirmed gaps within the literature. As a result, the researcher focused on the categories that were not well supported within the literature, for example there was minimal research for why individuals with health coverage were not adhering to their medications; the researcher went back through the participants' transcripts to find answers to the questions that were not consistent with the literature.

Furthermore, throughout the data analysis the researcher consistently met with the primary supervisor. These meetings became essential as there was discussion after the first few interviews to modify the interview guide to address the purpose of the question. Furthermore, as interviews progressed there was constant discussion around themes that emerged throughout the interviews, with a realization of what the predominant themes meant, which impacted the overall analysis. After the initial analysis, the primary supervisor provided extensive feedback that required the researcher to go back through participants' transcripts with a more objective outlook on participants' experiences. By going through this process, themes and categories changed with a focus more on an overarching realization of a common theme of the meanings that participants associated with their medications. By engaging in continual discussions and having the primary supervisor provide feedback on the initial analysis, it ensured the validity and reliability of the results.

By following the methodology of constructivist grounded theory, the results are presented in explicating participants' meanings and actions associated with living with a

chronic condition. Meanings were co-constructed between the researcher and the participant. Thus, when reading the results section there needs to be awareness of the voices of the participants; however, the researcher provided perceptions and descriptions of what was said.

#### **Chapter 4: Results**

The purpose of this study was to develop a theory on the process of decision-making regarding medication adherence in individuals between the ages of 40 to 55 who are required to take three or more prescribed medications. Specific organizational factors from the literature (i.e. the costs of health care, individuality, patient-physician communication, and Canada's health care system) were evaluated and served as a basis for the development of interview questions, which led to the discovery of predominant themes. Based on the experiences of participants, themes emerged around 'balance of medications with the rest of my life', focusing on the key concepts that kept re-emerging throughout the interviews.

The ability to self-manage one's health, relative to balancing of multiple medications, led to variance of choices among participants. Self-management is not necessarily an indication of engaging in positive self-management strategies but is referring to how an individual manages their medications in relation to their life, leading to decisions of adherence or non-adherence. Balance of medications with the rest of the person's life emerged throughout the data with underlying themes of individuals referring to sacrifices in certain aspects of their lives, the inability to function because of their prescribed medications, and rationalizing not adhering to their medications. This resulted in fear – fear of the future and fear of having to be dependent on one's medications,



which was ironic because even when dependency was recognized this did not result in adherence. Finally, by the individual having to manage their condition and even when the person felt ‘in control’, this never resulted in a sense of security. Security was not possible because of the constant decisions individuals with a chronic condition have to make on a daily basis.

The data serves to answer the original research questions of determining the factors that influence individuals decision to adhere to a drug regimen and understanding how specific factors affect the person’s ability to adhere or not adhere to their prescribed drug regimen. This project focused on giving a voice to participants and providing respondents the opportunity to share their experiences of living with a chronic condition, potentially for the rest of their lives. For a more comprehensive list of quotations to support the results outlined, refer to Appendix G.

### **Ability to ‘self-manage’ chronic conditions and multiple medications**

The ability to manage a condition was multifaceted in those living with a chronic condition (often co-morbid conditions). Some participants spoke of engaging in self-management strategies while others spoke of their ‘excuses’ for not doing so. For some, if they could continue to work (maintaining the privacy of their condition), became a method to self-manage their condition and medications. While almost all individuals did not want to rely on their medications *‘I’m a failure because now I have to take pills, pills are for old people – I’m not an old person’ -P4(4)* and almost all participants recognized that their medications only helped to a certain point and *‘[...] medicine that helps you cure something, hurts you in other ways’ -P2(7)*.

*Origins of chronic condition(s):*

Those who believed that they could have prevented their condition blamed themselves for having to be on their medications because of their decision to ignore the deterioration of their health. In their view, since their behaviors led to them becoming ill, changes in behaviour could also lead to controlling or even reversing their medical condition(s). In other words, self-management created the problem, so it should also resolve the problem.

*Maybe it is my fault because when I hurt myself I took a few days off and I thought that was treating it. I didn't even dawn on me to go to physio or anything like that. I just thought this is the job, you end up with a sore back and you suck it up [...] I like to get up and I like my clients but now I can't do anything. And I don't see it changing, I don't see my back getting any better, it's been a year and a half. -P8(1)*

*Well I know exactly how I got mine [referring to Parkinson's disease] it was from getting hit. If you go to the CNE and ride the bumper cars for a couple minutes, banging into things, the buzzer goes off, you get off. But if you do that all day long, 4-5 hours a day for 30/40 years something is going to happen and fall off the map, and that's what happened. -P12(4)*

Those who did historically ignore their bodies' spoke of adhering to their medications and wanting to do more to manage their condition because of the blame they already placed on themselves for having to be on multiple medications. Some individuals were more likely to adhere because they thought their condition was 'their fault'. It was a prevalent theme of individuals aware that something 'was not right' before they went to see a healthcare professional. As James outlined, it was easier to make excuses than to face the reality of it. This was very different from individuals who felt that their condition was not their fault but that due to genetics they were 'predisposed'.

*I have something that's genetic; actually he has it too, my doctor. That makes me say you ate what I ate and we both ate the same thing. I would*

*get sick and you wouldn't. I have a certain type of cell that predisposes me to get what I got. -P10(2)*

*They said do the exercise and watch your carbs and all that stuff but honestly I think if it's going to happen to people, it's going to happen. And I'm totally predisposed with my whole family. -P1(1-2)*

Those who felt they had no choice in their health because of being predisposed to their chronic condition, were less likely to engage in self-management strategies and despite their condition being viewed as inevitable, purposely did not always take medication or take any preventative action. Individuals who were 'genetically predisposed' or viewed their condition as their 'fault' had a sense of awareness of their condition and the medication needed to manage their condition.

This mind frame was very different for those who had a mental illness, who were often unaware of their behaviours and how it potentially impacted others, *"I hadn't realized what I was like and I think that's it. I think I'm totally normal"-P1(5)*. It often took loved ones to let the person know how they were acting for the person to be aware of their own behaviours, as their lack of awareness of their behaviours was a result of making the decision to not adhere to their medications.

*The impact of others to self-manage condition and medication use:*

Loved ones also became a central role in many participants' lives in managing their condition and medications through the support of helping the person integrate their 'new' self with their 'old' self. This support came in the form of aiding the person in making the first steps in asking for help, in adhering to their medications, in engaging in self-management strategies such as exercising and healthy eating, and potentially the most

important form of support – helping in tasks the person was once capable of doing but was no longer an option. However, not all were fortunate enough to receive any form of support and at times had to manage alone.

*I have difficulties with the people in my house and my diabetes and finally my husband is a huge problem and I think I've finally got it through his head that we can't do this I need to eat at 6 o'clock we cannot eat at 8:30 at night. Like we're workaholics in our house, all of us are and that's not a good thing [...] I don't know he doesn't care, he just ignores me [...] How have I been supported? I support myself. I come here, I do my exercises I do my work and I get no cooperation from anyone about anything so basically I just truck on. -P5(6)*

*[...] I grew up with the mentality 'you're fine, why can't you be happy'? You know my parents used to be like 'why are you so unhappy? What's wrong? Why can't you be just fine? Just think nicer things'. You try to do that but it still has that stigma...-P1(2)*

In the accounts outlined above, participants saw no other choice but to manage their condition themselves. This led to an increase in non-medication engagement strategies, such as dieting and exercising, and these individuals were more likely to pay for additional treatments such as physiotherapy and counseling. However, this did not predict medication adherence – all admitted at some point to non-adherence, questioning if there were support mechanisms in place, would they be more likely to adhere to their medications?

Those who had support recognized the power of support in helping them manage the challenges they face every day.

*...a lot of time I can't pull up my frigin pants or hold a fork or whatever. He [referring to her husband] does it with stride. I can't open bottle – he does it for me, little things that are stupid. I'm frigin 46 years old I should be able to open my own bottle. -P9(5)*

*My husband is a great supporter. Ken is really good and if I do ever get in anxiety attacks or anything he'll just be like 'you're okay, you're here...we don't need to do anything, take some deep breaths, think of something else'.*

*He's really good. My kids know about it, they're all good, they know I go up and down kind of thing. -P1(4)*

Individuals were able to manage their condition with the help of their partners, who often helped with their drug regimen. The medication became something significant to their partner as well because they saw the value in their partner adhering to their medication, so would help if possible. Other participants discussed a process of support that only developed when their partner also experienced a setback in their own health. This helped their partner to fully conceptualize what they have had to endure and to justify having to be on multiple medications.

*I think Ken did and said I'm not sure if this is a good idea but you see at the time Ken wasn't taking a lot of drugs either. So he was like 'why are you taking a lot of drugs'? But now you see he has too, so he realizes that those drugs are keeping him alive while these ones are keeping me alive. So I don't think he was as supportive back then as he is now. -P1(5)*

This illustrates the lack of awareness regarding management of a chronic condition and how an individual with a chronic condition rely on their medications to help them manage their conditions. The support from loved ones seems to influence a person's decision-making regarding their own health. Whether it is in the form of positive or negative support, the person with the health condition is aware of what they need from others. However, in the end it is the person who is on multiple medications who decides to engage in self-management strategies.

*The 'success' and 'failure' associated with self-management:*

With some making the effort to engage in self-management strategies, some were confused as to why they were still diagnosed with a physical condition, *"I exercise I don't eat bad and I run now so there really isn't any reason why I should have high blood pressure"-P10(4)*. Others were aware that they should be engaging in some form of self-

management strategies beyond taking their medications but still have been unable to do so. This was attributed to age, stress at work, routines of everyday life, and not having the time. All participants knew they were making excuses and placed blame on themselves for not being in more control of their health.

*I don't know if it's just the lifestyle we have now a days, it's so readily available – you have a big TV, you have movies, sports, watching hockey. I mean you get the exercise bike you can sit and watch it while doing it or take the dog for a walk. Walk the dog a couple of blocks every day but you just make excuses and it's easier to fail then to actually succeed. -P4(5)*

*I got a hole in my stomach and the surgery was in April and it didn't heal until September. And that's probably part of the diabetes, which is my fault. It is what it is; we stopped and never have gone back to it [referring to going swimming]. We want too but we have never seem to have gotten around to it. -P1(7)*

By not engaging in other strategies besides taking their medications, James and Abby spoke of blaming themselves and the fear of failing. Despite Abby's disinterest in doing more physically for her health, she has admitted to being a 'pill popper'-P1(2) for her 'physical conditions'. This shows the complex relationship people have with their chronic condition and the rationale behind selecting treatments, in that individuals are not following all suggestions but are determining what works within the context of their life.

Those participants who have accepted that they may have their condition for the rest of their life, wanted to do more to manage their condition and wanted to have greater control in managing their medications.

*When I got injured I didn't know the first thing about arthritis, it wasn't in my family. I didn't know the first thing about disability, any of that stuff. Until it happens you just go on with your life but I'm not a passive personality. Some of this I can control, some of it I cannot control. I think it makes me feel a little more balanced; education is where that balance is and what's for me to find out and to do my homework sort to speak and when to seek out answers. -P2(5)*

Individuals became aware of what they had to do to manage their condition, recognizing that medication alone was not enough. This was also reiterated by participants who wanted to self-manage their condition by being able to seek additional help but who were unable to do so because of many factors, including: the time it took to receive help when it was needed, the out-of-pocket expenses, and not ‘qualifying’ for help when requested. For example, Abby spoke of wanting to see a psychiatrist since she knew this could help her with her depression but she recognized that by the time she was able to see this specialist she would have already forgotten her problem.

*I had a really bad time and I went to see her [referring to family physician] and she asked if I wanted to see anyone else. I said no because I go to see her I get the appointment the same day, right? By the time I get an appointment with a psychiatrist, those feelings will be gone and I'll sit there being like 'I'm fine, how are you?' -P1(3)*

For those with a mental illness, many spoke of wanting counselling but were unable to do so because they could not afford it or had to wait until they were at a ‘low’, which justified their out-of-pocket expenses. This is a fault in the system since many recognized the need for treatment beyond medications.

*I think one thing that's missing in all of this is some kind of counselling and how illness can impact your life because I called up the mental health people after I had the incident on the street and said I think I need to see somebody, this is really scary what happened here. They asked me all of these questions 'are you suicidal'? No I'm not suicidal. 'Are you clinically depressed'? No but I'm in a tough situation and I think it would be best to talk to someone, to have a neutral third party that's not involved. 'No we can't do that, it's not available'. And I thought the stress that comes from having a chronic illness, the leg that's not being addressed here is mental. - P2(11)*

These feelings resonated with many participants – living with a chronic condition is not something that is short-term and there is a greater need beyond medication. Participants felt there was something inherently wrong when medications were covered through

insurance plans but having the opportunity to speak to someone about their experiences due to their condition(s) was not.

For individuals to be able to afford their medications and any additional out-of-pocket expenses such as counselling, almost all participants spoke of having to be employed. Being employed became a form of self-management as it allowed individuals to afford additional resources beyond medication. Employment also played another important role for participants, as it provided a method to maintain a part of their life that gave them a sense of ‘normality’, in that they could resume the life they had before they were diagnosed with a chronic condition and having to take multiple medications.

*The ability to continue to work and maintain privacy:*

Many associated being employed with achieving a sense of normality and this was viewed as a reflection on their capacity to self-manage their condition. This became related to the ability to maintain the privacy of their condition and their medication use; many spoke of the importance of wanting ‘no one’ to know ‘anything’.

*I'm surprised I'm saying all of this [...] Because I'm so private with my medication, I mean nobody here knows anything [referring to workplace].- P6(4)*

By maintaining privacy it allowed participants to continue to maintain elements of their ‘old’ life before they had to take multiple medications. For example, working affirmed that their condition(s) and medications were managed, as they were able to maintain that part of their old self who was able to work and keep their condition private because of the ability to maintain who they once were and avoid ‘being treated differently’-P13(9).

*Well I was diagnosed with Parkinson disease 14 years ago but I kept quiet about it for 13 years [...] I ran into the problem that I had to hide it. I had to hide it from everybody and that became more of a problem for me*



*because if everyone found out I had Parkinson's disease I thought that they would shun me away from any TV or projects I wanted to do. -P12(1,3)*

Simon spoke of the need to 'hide' his condition to be able to continue to work because of the fear of what others would think if they knew he had Parkinson's. For Simon, his medication became pivotal because he had to be able to manage his condition to ensure the privacy of his condition. Some participants went as far as not telling their family of their condition or that they had a heart attack to protect them, *"you can't talk to your family about that kind of stuff [referring to her personal health] because then I worry about them worrying about me"* -P2(11). Julie had a strong belief in self-management and made the decision to endure her condition alone because of her strong beliefs in privacy and not wanting to place stress on anyone else but herself.

For some they were unable to self-manage their condition, even with medications, and had no choice but to quit their job or were limited in their workplace and in one instance it also resulted in losing loved ones.

*I don't want to continue like this. It's affecting my work; I can't be at work as long as I would like to be [...] my grandkids for picking them up and stuff. Going out and just doing regular activities and things, I'm limited for what I can do and for how long, so it's difficult. -P15(4)*

*[...] it was 4 years into the period [referring to not being diagnosed but ill] that I didn't work she was tired of quote "of looking after me" quote. We had a young child at the time I think her comment was "I don't want to look after 2 babies". She had gotten a promotion and I had found out she had gotten a boyfriend. -P14(4)*

Being on medication only helped manage participants' symptoms to some degree, but the side-effects still limited their ability to think clearly and they did not have the confidence in their ability to return to a working environment or could only work for a certain period of time and felt defeated because they wanted to be able to do more. For Peter, his

inability to manage his condition with the proper medication caused loved ones around him to lose confidence in him and it resulted in him losing his wife and child. Julie also spoke of a similar experience of not being prescribed the proper medication and unlike previous examples where participants chose to quit their jobs due to their condition, Julie was fired from her job because of her medication.

*Then in December I passed out, well almost passed out but I didn't pass out. My blood pressure was so low; my pulse was so low like it was at the general meeting. So managers were all there, whatever, the OA here was serving my lay off paper the next day [...] I was flipping. I had to go to my union rep. What had happen was the pharmacy screwed up; the name on the bottle was not the medication in the bottle. I wasn't supposed to take it in the morning; I was supposed to take it at night. It was like 3 weeks, I was a zombie. -P13(3-4)*

Julie adhered to her medications and instead of resulting in an improvement in her life, it meant losing her job and losing the privacy she had tried so hard to maintain in her life. Thus, her medications became the culprit in her job loss, and she cultivated a complex rationalization of timing her decisions to consume or not consume her medications.

The theme of 'self-management' demonstrates the variance in behaviours and choices between individuals who are diagnosed with a chronic condition (often overlapping conditions). Engagement in self-management strategies that involved the person choosing to do more for their health was not an indication of medication adherence. For example, a person who exercises to control their blood pressure may not take their medications, whereas another participant may take their blood pressure medications but choose not to exercise. In the current study, the perceived origins of their medical conditions, support from loved ones, employment, and the ability to maintain privacy, all intertwine with perceptions of self-management to contribute to the choice of consumption of medications.

### **The choice of sacrificing medication use**

Despite the reliance on medications to function, which many experienced through non-adherence, this did not predict the decisions individuals were making to continue to live their life. Almost all participants spoke of having to making sacrifices that affected their health because of the costs of their medication, the costs of additional treatment, and making the choice to provide for others versus themselves.

*'Meds are very important but...':*

The costs of medications can often limit a person's decision to adhere to their medications. This was expressed by some that because of the expenses already in their lives (i.e. car and house payments) and having minimal coverage, sacrifices were often made:

*They want to remove some of the tissue, they want to remove half of it so it releases the pain but they won't cover it for this one [referring to her left breast]. So I have to pay \$6 000 for this one [...] I was supposed to have surgery July 16<sup>th</sup> but I cancelled because I didn't have the money. -P13(2,9)*

*I don't go buy new clothes when I see it or I'll have to do without [...] I cut down on groceries, certain things I would've bought before. \$10 t-shirt even, I cut back because I know my prescriptions are \$250 I have to back off on other things, so we did [...] as long as I have my pills, I'm okay or I would be sitting her sweating. -P8(5)*

Sacrifices were made that resulted in individuals not taking the recommended doses to make their prescriptions last longer, limiting spending even for basic necessities. Krista and Julie associated costs with their health. For Krista this meant having to decide what medications were essential while not adhering to others in order to cover the costs of prescriptions that were viewed as a 'necessity'. Julie had to determine if medical treatments were deemed as 'necessary' if it meant out-of-pocket expenses that were not

feasible based on her current prescription costs and having already maxed out her benefits.

Individuals also attempted to rationalize their medication consumption, and despite doing everything possible to provide for themselves and their family, it was often not enough. This resulted in, *“I would miss pills for a couple days because I didn’t have the money [...] I mean meds are very important but I mean I have to feed the kids”-P7(6-7)*. For some, this meant rationalizing not taking lifesaving medication and losing function, however, there was more value in providing for others versus themselves. Julie spoke of losing her coverage and being unable to afford her medications but decided to sacrifice her own health to aid her son in buying a new house, *“I’m giving him my savings to buy it [referring to a house] for him and his girlfriend”-P13(9.)* Sacrifices were made because to some there was no other choice. Lauren and Julie associated greater meaning in being able to provide for their family as opposed to the value in their medications; recognizing that having to take multiple medications does not only impact the person but others as well.

### **The fear of living with a chronic condition**

‘Fear’ was a feeling all participants were able to resonate with. There was constant fear of the future with a focus on the fear of losing one’s medication coverage despite having medication coverage and fear from comparing themselves to others who had the same condition. Fear was also directly related to the increased dependency on medications and the fear of what this entailed – medications were essential for the person to live even if this meant having to live with the side-effects. This required participants

constantly having to make decisions regarding their medications, which lead to the question of, ‘have I made the right decision?’

*The fear of the future:*

Individuals living with a chronic condition have to constantly make decisions regarding their health affecting their ability to ‘live’ their life. Almost all participants spoke of having to be on their medications for the ‘rest of [their] lives’, which resonated with feelings of fear because of the implications of this. The word ‘fear’ was not necessarily used but below the surface it was apparent that individuals were constantly thinking long-term of what could happen because of having to be on multiple medications. This led to discussions around medication coverage. The majority of participants had some form of coverage but there were diverse views on ‘would I adhere if I did not have my coverage’?

*The costs are fine because Ken’s plan is really good. If I had to pay for it on my own [...] I’d probably still do it because what would the consequences be? So I’d probably have to find some way of doing it. -P1(6)*

*I’m covered for everything right now and I have a really great pharmacist who doesn’t charge me the little bit extra [...] I worry about when I retire though because I’m on already a slew of meds and as you get older you just get put on more meds, so this is going to be quite brutal, so I worry about that but then I think I’m not going to retire so it doesn’t matter. -P3(8)*

Participants hypothesized what would happen if they lost their coverage at retirement or from some other reason even though this question was never asked. Abby outlined that she would have to find other strategies to cover her medications because she was not willing to experience the consequences of non-adherence and was aware of her dependency on her medications to function. Participants considered the future and what being on medications entailed – how there is this deep realization that there is a

dependency on medication to live and thus on medication coverage to be able to afford to live.

Many participants recognized how grateful they were for their coverage yet this also meant having to live below the poverty line to qualify for medication compensation. Those who suffered from depression, anxiety, or were simply overwhelmed by having to live with a chronic condition every single day, outlined the need for better treatment beyond having to take multiple medications.

*[...] John's work covers the cost of medication but it doesn't cover the therapy. So if I go in to see a psychologist, it comes out of my pocket or John's pocket, that's hard so I really pick and choose when I need it. So if I'm really low then I'll go see them [...] it runs from \$150 to \$250 per hour and nothing is healed or fixed in an hour. Right now I know I have to go to therapy and I have this lady on speed dial and I'm just waiting. It's like 'I'm okay, I'm okay I think I don't need it, I'm okay today' because all I have to do is call her and get in that day but I know one hour is not going to do enough so 5 hours at \$200/hour. -P9(6)*

*[...] for me to go see a therapist privately is a minimum \$140 an hour, I don't have that kind of money and the reason for that is I have to be so broke to get my meds covered. -P2(11)*

The costs of alternative treatments, such as counselling, effect an individual's decision-making by forcing them to only seek counselling when it is potentially too late.

Individuals are then living in fear of the unknown because there is an awareness that individuals have to wait until there is no other choice, questioning whether those who suffer from a chronic condition could better manage their condition if the option of additional treatment was available. The fear of the unknown was not limited to the costs of treatment and medications but the fear of what could happen due to their condition.

This resulted in many individuals comparing their condition to others who were

diagnosed with the same condition and had experienced something negative due to their condition.

Participants spoke of individuals they knew who had died because of health related issues. This led to varying perceptions of their conditions, with some viewing death as inevitable while others were fearful of what could happen.

*I do know one guy who died in his sleep from a diabetic problem, he was insulin diabetic and he went to sleep one night and didn't wake up. So I think it's' fear that if I don't take those ones, the physical ones that something is going to happen. -P1(5)*

*My dad passed away from leukemia he didn't know, he had gone for a checkup 5 months earlier then he passed away and then my brother just over a year later passed away and he was 51 at the time but he didn't really take care of himself. I mean heavy smoker and his eating habits weren't the greatest. I kind of was like when I'm 50 I have to go and see him [referring to his family physician]. -P4(2)*

In James's case the fear of seeing his father and brother pass away, led him to see his family physician and get diagnosed with type 2 diabetes. By witnessing the death of a family member, it seemed to put life in perspective. For Abby, the fear of what could happen if she did not manage her condition resulted in an increase in adherence for the 'physical' medications but this was not a consistent behaviour with her other medications.

When outlining the impact of their conditions, there was often a comparison to others who were diagnosed with similar conditions. Participants sought affirmation in knowing that they were not the only one who was ill, some went as far to outline that they were more in control of their condition compared to others.

*I've seen other people recently as recent as last summer that were playing with their medications and they were suffering from depression but they weren't handling it, they were abusing it. Where they would self-medicate*

*dosages, it would be like I'm going to meet people so I'm going to take a handful. No, now you're just high. -P11(4)*

Individuals would compare their experiences to others often in an attempt to figure out if what they were experiencing was 'normal'. Fear then became associated with what could happen if non-adherence took place and how dependency of medications can become an addiction.

Despite the comparison to others, which resulted in fearing for the future because of the awareness of what living with a chronic condition could entail, this did not predict medication adherence. Once again there was variance in adherence behaviours with some believing they needed certain medications over others (thus, choosing what medications they needed) and others having an increased dependency on their medications, with some fearful of what this meant.

*The fear of dependency on medications:*

All participants recognized the need of their medications to live their life yet this was contradicted by almost all participants who, as interviews progressed, admitted to purposely not taking their medications. However, for some there became a moment when they realized that despite not being able to have 'tangible' results with their medications, their experiences reaffirmed the value in adhering to their medications.

*Well I'll tell ya, it's an oxymoron, I'm a pill popper with the Metformin and that but I just get to the point where I'm like I'm taking way too many drugs and I would stop taking for something like that because depression I think for the last 10 years has never been realized as a disease and see I grew up with the mentality 'you're fine, why can't you be happy'? I could lose that one and could be happy but I can't lose the Metformin because that's tangible, you can see it, the blood pressure. -P1(2)*

*[...] we were on the water and I got one on the bike and I almost took him and me out on the bike. And I had stopped taking the medication because I had gone on it at first but I'm better now, everything is good. When that*



*happened I was just beside myself and my doctor said 'oh my god you never should've gone of that. You might just need that, you might have to be on it for the rest of your life, you might just need that edge'. -P10(2-3)*

When people could not see the direct benefits of their medications or that their condition was not recognized as a 'disease', for them it was an indication that they no longer needed their medications. However, participants associated that because they were 'taking too many drugs' and the effects of their medications were not 'tangible' – the meaning in the medications altered because they no longer wanted to be dependent on something.

Those who suffered from depression or anxiety had a very different meaning associated with their medications than others. There was a greater fear in these individuals because almost all recognized that certain situations would trigger a heightened awareness of the need for their medications and that they could not control their condition during these situations with self-management or their prescribed doses of their medication.

*Sure I've got the medication but the medication is okay but that's not going to last me forever...if anything slight goes off in my family life. -P9(6)*

*I'm a single parent. And I was briefly married [...] I shouldn't say briefly it was 7 years and he was a gambler and I found out about that after. He disappeared a few years ago, I have a feeling people were after him but he left without saying anything to her either. -P3(7)*

Certain factors such as fear, having to care for others, relationships ending and becoming an empty nester were all linked to stress. Stress was a factor that led certain individuals to perceive they had less control of their condition(s) and in some circumstances resulted in higher dosages of their medications.

Many spoke of the dependency on their medications to function in everyday life. Some recognized that without their medications, they would not be able to live any type of normal life, resonating with feelings of fear because of the unknown, what would happen if their prescription ran out, if they lost their coverage, or if their medications no longer had the same effects. For some, the fear of dependency could be addressed by reducing their consumption of medications. They did not want to put ‘pills’ in their body because it would eventually increase their dependency on their medications.

*[...] and I said to Marcus if I don't have my morphine tonight, I will be going through withdrawals in the morning and I'll be basket case – I won't be able to do anything. -P9(4)*

*I don't want to take it but I can't function, I have to take it. Like the Celexa, the antidepressant thing there, no I can do good with that low dose I don't want to be on anymore then I have to be on and that little bit is sustaining me. So I'm good with that but the other medication I have to take it or else I won't be walking down the street and for Estrogel if I didn't take it I wouldn't be sleeping. So to function in life you need sleep and I need to walk so. -P10(8)*

Medication became a means for participants to ‘function’ in their life but this was not an indication of the person ‘living their life’. Faye clearly outlined how many participants felt that adhering to prescribed medications was a contradiction – one needed their medications yet even when one took their medications this did not always mean one could live the life they wanted to.

*With my morphine I take, still today, it's been 2 years; every morning when I take it I can't function for about 2 hours. Every night I take it, I'm a write off because you know my body is just and you know with the hydromorphine you should be able to work, still be able to drive a car and live a normal life, you're body has come accustomed to it, my body wont, it refuses to become accustomed to it. -P9(4)*

Faye's experiences spoke to many participants' experiences that even with a dependency on medications this did not always equal functionality, yet participants would still

continue to take their medications even though this did not allow the person to ‘live a normal life’. Living a normal life was related to the person being able to perform tasks they were once capable of doing; however, due to restrictions of their condition and often the side-effects associated with their medications, this resulted in limitations and having to come to terms with their ‘new normal’.

### **Identity dilemma of the ‘old normal’ to the ‘new normal’**

For many living with a chronic condition it resonated with feelings of being ‘disappointed’ in themselves and ‘too young’ to not only be diagnosed with a chronic condition but on multiple medications. All participants spoke of the moment when they were diagnosed with a chronic condition and what this experience meant to them. This became the pivotal moment for many having to shift from who they once were to moving to a ‘new normal’. A new normal became *“having something that is moving forward is really, really important [...] if you have no sense of possibility you get stuck”*-P2(13). Individuals had to find ways to move forward, which involved medications.

#### *Emotions associated with being first diagnosed:*

When individuals first heard they were diagnosed with a condition, it became a pivotal moment in their life. There was variance in emotion with some being ‘upset’ while others were in shock, almost in denial, because they perceived certain people to have certain conditions and they did not think they would ever be one of those people who were diagnosed with a chronic condition.

*I was really upset because I’m not a medication person and at the time the only thing I ever took was Tylenol when I had pain. So when I first found out and I was put on medication because they also found out I had the osteoporosis as well so I had to go on medication for that and I cried and was really upset because I’m not a pill person. So I felt a big huge setback kind of thing. -P15(1)*

*And the diabetes was a complete surprise to me [...] I didn't think I was the type of person for diabetes – there was no history in my family, I was not a heavy person at all until after I quit smoking and when I was younger I was pretty active but smoking and the job and lifestyle just slows you down. But I really didn't think I was a target for diabetes. -P11(2)*

Being upset and surprised with the diagnosis meant for many having to be on medications. This to some was more upsetting than knowing they had a chronic condition because it entailed having to be on medication, which to them was viewed as 'failing'. Others found solace in their diagnosis because for them it provided an explanation of what they were experiencing.

*I think it actually was kinda a relief that I could chalk this up to me not being an ass. -P11(3)*

*Relieved [...] because I had 10 years of symptomology with no diagnosis and I've been unable to work and I was fighting insurance companies and I had seen 27 specialists so finally someone put a name on it and the insurance companies get happy and life is good. -P14(1)*

By getting diagnosed this provided affirmation of what they were experiencing. Before their diagnosis, both Peter and David had to deal with others, including health care professionals, questioning if they were sick. Medication to them was viewed as a relief and became an opportunity to help them manage their diagnosed condition.

Another emotion that emerged with being diagnosed with a chronic condition was the realization of what the condition would entail and the severity of having that condition.

*I was furious. I don't need this on top of everything else. Neuropathy is a very difficult thing to live with; it's like having electrodes in your feet. I know this sounds every dramatic but it feels like barbed wire being pulled through the feet and I have no feeling on the surface of the skin but internally you get this electric sensation. -P2(4)*

For some, their ‘new normal’ was associated with heavy emotion and recognizing the impact of their condition on their lives. Participants had different reactions and emotions associated with their initial chronic condition diagnosis. For some it led to feelings of sorrow, shock, and anger, yet all were aware that being diagnosed also meant having to take prescribed medication. This became the starting point of their ‘new normal’.

*Moving to a new ‘normal’: dependence vs. the imagery of a warrior:*

For those with a chronic condition making the transition to a life that involved having to take multiple medications on a daily basis became a challenge for all participants because of what their medications stood for. For those with a mental illness, many spoke of specific experiences that have contributed to their reasoning of having to be on prescribed medications.

*It [anxiety] got triggered by my mother died 10 years ago and I was executor, what a nightmare [...] when she died, they took us to court and wanted their share, which wasn't much anyway. You figure a house that's worth \$100 000, you're dividing it by 3 and by the time you take the lawyer's fees and everything, cremation, whatever there's not much left. But they insisted they were going to do this, it was a big scandal. The lawyer who handled the case did something wrong and in the end committed suicide, it just goes on I can't even explain and they blame me. I've never hurt a flea and I think you know that. And I took it to heart so I ended up getting these panic attacks so bad. -P10(2)*

*I had post-partum with my daughter and that's when I was diagnosed with the blood pressure, she was a year old. And I wasn't in a good relationship at the time with her father so it was a lot of stuff happening [...] my son was demanding and stress with him and he lived out of the home for a while, at a treatment centre because of his issues and stuff. -P7(4-5)*

Drastic life events led to the diagnoses of certain mental conditions, which resulted in the person having to take prescribed medications, requiring the person to recognize that something was wrong and their life was no longer ‘normal’. Having to take medications became a reminder that ‘normal’ was gone and medication was needed on a daily basis.

Other participants spoke of who they once were, not necessarily contributing their diagnosis to a life event, yet emphasized what they were once capable of doing and caused them to reflect on who they have become.

*I always thought I mean through my life you wouldn't notice now but through my life I was always into weightlifting, I exercised like religiously every day up until after we had the kids and they start growing your lifestyle changes you don't have that I mean when they got a little bigger I got back into it but then it fell by the waist side. And I thought I took care of myself and thought I ate very well I just was shocked that he said I had it, what the heck you know, I couldn't understand why. -P4(2)*

*My whole life has been about me, where I played, where I coached, the towns I've been in – it's time for me to balance the scales a little bit. And I don't mean to be selfish but everything evolved around me and now it doesn't and I like it. I can give back; balance the scales a little bit. That's the great thing about it and I feel like what I'm supposed to do. I don't want to be remembered as Simon the great hockey player, the great coach, the great TV guy, great writer I rather be remembered as the guy who raised a lot of money for Parkinson's disease. -P12(5)*

The experiences above document the differences in how someone with a chronic condition can perceive themselves. James had feelings of 'shock' and associated himself with being a 'failure' because of the person he once was while Simon recognized the changes in his life and what he could do as a result of his condition. Simon was one of the very few participants who adhered to his medications, which may be contributed to his ability in wanting to be proactive about his condition and because of that engaged in self-management strategies and medication use.

Moving to a new normal and realizing the importance of medication also became a means to perform everyday functions. Many participants were diagnosed with some form of arthritis, which meant for them having challenges every morning getting dressed, being unable to work because could no longer type, going to the bathroom, and "*just simple little things*"-P6(5). Individuals felt frustrated, useless, and felt as if they lost

their independence because they had to rely on others for help; this was not limited to those with arthritis but with almost all participants. For some this also meant losing control of areas they once were in complete control of.

*And then they tried to, Ashley and Dee, both knew about my diabetes so they tried to over control what I was eating. And I did lose it on them and said you can't control what I eat, I'm an adult and I will control it. You guys can be aware of it but I can control it. So then I slid backwards and started eating cookies a lot because you know my daughter is there and is 16 years old and she doesn't have any issues so well we can't cut her off because I can't eat them. So okay I'll have a couple and Ashley is the same, she will bring in treats for herself and I told them I'll eat what I want, when I want. - P11(6)*

Living with a chronic condition, often co-morbid conditions, forced participants to figure out what they could and could not do, which was difficult for many because it often came back to individuals speaking of how young they were and this is not how they anticipated their life to be. However, not all were willing to easily adjust to a new normal instead sought affirmation in knowing that they were still able to maintain the identities they previously had before being medicated.

*I mean I think I'm a good wife too, I cook and clean I do it all. -P10(9)*

*If I can go, I can go until I drop. That's what I do. -P10(9)*

*I think the nuns they always said 'fight, fight, fight'. So my attitude is totally different than my sisters. My sisters are scared; they panic when they are in the city [...] they're not fighters or pushers. I am. -P13(6)*

While Mikaela and Julie affirmed who they were in certain roles as being a 'good wife' and being a 'fighter', others focused on how strong they were, "*I've battled back from anything*" -P12(1), creating images of themselves as a warrior and being able to 'battle' their health, as if their health was the enemy. Others saw their condition(s) as another opportunity to prove that, "[...] *then I thought this is just another thing in my box that I*

*have to tackle [...] I can do it, I can get rid of anything, I can do anything”-P5(3).*

Nicole presented herself as being able to do ‘anything’, as if her health was just one more challenge she was capable of conquering. The ironic thing in how participants viewed/represented themselves as being a ‘fighter’, being able to ‘do it all’, and ‘battling back from anything’, yet all spoke of the struggles they have had in managing their conditions and medications. To some degree all spoke of, “...*they* [indicating health care professionals] *told me none of them* [referring to medications] *I would be off of unless they will change to another one [...] this is for the rest of my life.*”-P13(3). Medication became the means that allowed individuals to function and thus to have the belief in themselves to ‘battle back from anything’. It also meant individuals creating routine to address concerns with their medications.

For participants who had a greater sense of awareness of the effects of their medications, they realized the importance of incorporating their drug regimen in their everyday life.

*Every morning when I get up I have my breakfast first then I take it because I don’t want to have an empty stomach [...] So I put my one right there when I have my supper then I take it right after I have my supper so that I know I’ve taken it. -P10(5)*

*[...] what I do is I take my meds and then once weekly I set up a regimen so I have morning pills, evening pills in containers. -P14(2)*

When asked how the person incorporates their medications into their lives, some outlined creating a routine, emphasizing that the drugs were incorporated into ‘my day’. Even with a routine and a sense of awareness, Monica clearly articulated the challenges of being on multiple medications and even with a system in place that was not always enough.



*It was difficult and I wasn't writing it down, which I should have but I didn't have adequate pain management so I wasn't sleeping well. And when you don't sleep well that makes you not think as clearly and I was making mistakes. Like I wear a fentanyl patch and in December I didn't take the old one off before I put a new one on [...] I was so tired and spacey. I wasn't making sure I was taking it off and I was found at a corner in the dead of winter unconscious in my chair with my dog tied to my chair [...] I had no idea that this happened, I could've been going across the street and just stopped in the middle of traffic. So I went in and talked to Mike [pharmacist] and Curtis [family physician] and said 'we have to do something, this is really serious'. I could've been killed, the dog could've been killed, whatever and that's when they came up with this [referring to bubble pack med kit] and it's worked like a charm. I haven't had any problems with it. -P2(3)*

It took a life-threatening experience for Monica to realize that being on multiple medications can be very challenging and a system that may have worked for others, did not work for her. Having a drug regimen entails the person being conscious of the mixing of certain medications, when and how often to take a medication and the onus is on that person to follow their drug regimen.

It was apparent that for all participants, a medication can only do so much to help the person live their lives. What was outlined to some degree by all participants was the contradiction with medications – it is designed to help but results in failure. Medication can only help to a certain point and this is assuming it helps to begin with, as Mikaela reiterated the medication she was on did not help her in anyway yet she was prescribed the medication. This becomes dependent on the person to make a decision to continue to take a medication that has been prescribed by their doctor or go against their doctor's recommendations because to the patient the benefits do not outweigh the side-effects. This becomes a difficult decision for a person to make and the communication of the

physician factors into the decisions that individuals are making to adhere to their medications.

### **Prescribing experiences**

Creating routine: being prescribed a medication forces an individual to have to make daily decisions to adhere or not to adhere to their prescribed medications. Even when participants made the decision to adhere to their medications, based on their physician's recommendations, this resulted in serious side-effects. While some participants were aware of the side-effects, others were not. If the person experienced a side-effect from their medication, from then on it became a risk for the person to take any of their medications. Individuals then had a heightened awareness of their medications because they did not feel confident in their medications based on their experiences with the negative side-effects. In an attempt to avoid the consequences of their medications' side-effects, individuals created a daily routine to incorporate their multiple medications into their life. As a result, medications became more than having to put 'pills' in their bodies.

#### *The awareness of being on multiple medications:*

Many meanings were associated with the concept of 'multiple medications'. Some spoke of their prescribed medications in relation to their age, "*I'm a failure because now I have to take pills, pills are for old people, I'm not an old person I don't want to take pills*"-P4(4), there was a stigma associated with taking medications and the constant challenge of individuals being relatively young to be on multiple medications.

Participants still questioned the value in their medications:

*I hate being on the medicine for 20, 30 years because what happens is any medicine that helps you cure something, hurts you in other ways [...] It really is heaven and hell. -P12(3)*

Simon outlined what was reiterated by many participants who have had no choice but to be on medication for quite a while and because of this their medication is less effective.

A majority of participants spoke of the awareness they have because of the effects of their medications.

*I couldn't figure out by the end of my career I broke my sternum, broke my shoulder, broke my collarbone, broke my wrist, broke my foot I couldn't figure out why it was all happening because I had really been bullet proof for most of my career and they did a map out of my history and they said 'you were taking Prednisone for so long when you were 16 that it softened your bone mass', so it became brittle at a certain age. -P12(3)*

*They put me on a TB drug for 6 months and its' a prophylactic for 6 months prior to going on Enbrel. And it's the same drug called Isoniazid, I took it as a child but when I took it a second time it caused this neuropathy reaction, which is very rare and caused permanent damage to my hands, mostly my fingertips and my feet are numb. It's very painful. -P2(4)*

Simon's experience, outlined above, documents how he had to deal with the long-term effects of taking a medication when he was younger that later would jeopardize his career but at one point that same medication allowed him to pursue his career. One medication for Monica, which she thought would be her 'magic bullet', resulted in her having a reaction and developing neuropathy. These experiences factored into the decisions these individuals made from that point on involving their medications because of the fear of knowing what could happen, resulting in an heightened awareness of their medications, which was not consistent among participants.

While many have recognized their dependency on their medications to function in everyday life, for some their dependency on their medications resulted in serious

consequences. Individuals reflected on their lack of awareness of their health and attributed this to their medications.

*I didn't realize anything was wrong with me to the point I would come home from work lay on the couch and tell her to get her own meals. She was 12 and I didn't feel like cooking, 'go make yourself something' but I didn't think that was wrong [...] I didn't sleep much and I thought that was okay too. I was on it [referring to Champix] for 8 weeks and I don't know. One day I had all my pills lined up and then I got scared and called someone and said 'I'm afraid I'm going to take these please come get me'. -P3(2)*

*I get really frantic and everything has to be perfect. I just go [...] I go in overdrive, everything has to be perfect and everything has to be done right now and when I crash, I don't care about nothing. Those dishes who cares about dishes, those paintings that are waiting to be hung that I was so crazy about hanging them 2 days ago, they can sit there for another 2 years, I really don't care. My biggest thing is I'll stay in bed; it's easier to stay in bed. I've taught John and my daughter, Lindsey, that it is better that I'm in bed then out because if I'm out then I think stupid thoughts. So if I think stupid thoughts I just go to bed and have a sleep...-P9(7)*

When reflecting on this experience, Liz recognized how abnormal her behaviour was but how it took a suicide attempt for her to realize the severity of her own thoughts. On the other end of the spectrum, Faye, who has bipolar disorder, was very aware how every day varied and was heavily reliant on others to help her through those days when she knew she had 'stupid thoughts'. However, both were adhering to their medications.

### **Patient-physician communication**

Physicians are a highly trusted source for participants. Almost all participants spoke of the value and trust they placed in their physician; however, despite this trust, this has not always resulted in positive experiences with their physician and the health care system in general. When a physician is unable to address the needs of the patient, often not in a timely manner, this led participants to purposely not follow their physician's recommendations because treatment was not catered specifically to their

individual needs. Participants spoke of the varying roles they play as a ‘patient’ and how this has inadvertently affected the decisions they are making pertaining to their own health.

*The role of the patient and the physician:*

When participants spoke of their experiences with health care professionals, it was apparent the varying roles patients took. Depending on what point the person was at with regards to their health, they were more likely to show emotions of vulnerability and needing someone to believe in them because they still were not diagnosed but were suffering every day.

*I went to a gynecologist and he said you're not going through menopause you're too young and he sent me home [...] the doctor just dismissed it [...] he said 'come back in 3 months or whatever we'll do blood work'. I come back, get blood work and he says 'you're full blown menopause', and I said 'what have I been telling you'? He said 'you're too young, the average age is 53'. I was 39 turning 40. -P8(2)*

*You know when you have someone coming every week saying something is just not right. In the end I cried because I had been to him a few times and I said 'something is wrong, I can't walk, I'm so lethargic and fatigued' and I had lots of the runs and it would come out of me and eat through my skin, it was horrible like the whole thing was a horrible, horrible thing. And in the end I said 'I can't do this anymore', I just cried and I said 'you have to help me, YOU HAVE TO HELP ME'. And he said 'I'm going to help you', he said 'we know it's something different' but a lot of doctors they don't know. -P10(10)*

If the person's physician did not address their concerns, participants spoke of feeling dismissed, did not feel value in their role as a patient, and often was not diagnosed until much later because of the physician initially dismissing their symptoms. However, other participants took ownership and recognized their role in their own health. As a result, they were more assertive with their physician and knew precisely what they wanted for their health.

*I require that and I would've kept looking for doctors that weren't threatened by the patient's next question and both of them are more than happy to answer a question. I also realize they have no time, so I don't ask them ridiculous questions. I come to them with well-considered issues and it may take them a while to get back to me but it's there [...] I have to feel like I'm much as a participant as they are and how the hell can I go to a doctor and say 'make me better', if I'm not doing my end. -P2(10)*

*[...] the doctor said the blood results are high and I said 'we had a birthday and I had a piece of cake' and I forgot I was getting blood testes right. So he says 'okay we can live with that' [...] then you start to look at the doctor and he's just diagnosing you on symptoms that you have. So you have to be upfront with him on what you are doing because if I went in there and my blood was 10 when I fasted for 18 hours and I didn't say I had a piece of cake and ate something I wasn't supposed to, now he's going to say 'well the medication isn't strong enough so we are going to have to up your dose or put you on insulin'. -P4(3)*

Monica and James did not blame their physician when they had any health related issues but took responsibility for their own actions. However, other participants were quick to place blame on their physician for any of their health problems.

*Dr. L is really good but I have to tell him what I want [...] I find it as long as I have to push him for him to send me for example to do these tests. I think that, I blame him a little bit that maybe it [referring to heart attack] would've been caught if he would've listened to me. Like I tried to explain to them, how would I know it is my heart with this [referring to her right breast] being so painful? - P13(7)*

Instead of taking any form of ownership for their health, for some it became easier to place the blame on others. Julie and Liz, both acted against their physicians' recommendations, and decided to take a medication to help them quit smoking. Both experienced severe side-effects and spoke of having no control over their thoughts and actions yet neither followed their physician's recommendations because they did not respect their physician or place value in what their physician said. Their relationship with their physician impacted their decision-making and as a result, both experienced serious consequences of not following their physician's recommendations.

David realized that one negative experience with a walk-in physician resulted in him wanting to have a family physician for the first time in his life.

*So I went to see him [referring to the walk-in doctor] one day and he asked me 'how I was doing' and I said 'oh I have a slight cold' and he said 'stay over there because I have 3 doctors out today and we can't have anymore out'. Well that's not really the response I was expecting, so ya I was not impressed with that. -P11(5)*

This was a common theme of individuals having a negative experience with a health care professional, which led them to seek better care.

*So when I spoke to my family doctor I said 'look if I'm going to talk to an infectious disease person, I'm going to talk to someone who at least knows what the hell is going on and spend some time'. So they set me up with the head of infectious disease at Toronto Western or no Toronto General. So I went down and met with him and he spent literally 2.5 hours with me doing a full workout. By the time I got home, I had an appointment booked for a follow-up within 5 days to go for some tests within 5 days after that I had an appointment with a follow-up with him and he said this is it. -P14(6)*

*I had a really poor doctor [...] the lady who diagnosed me; she was more upset that I had a coffee in there. I brought in a coffee and she said 'how dare you drink coffee in my office'. I was like 'pardon me'? She's a neurologist doctor and she was balling me out for having a coffee, why? I never heard anything like it and she said 'because I said so'. What kind of bedside manner is that? This is going to go downhill from here [...] she had no idea who I was or what I had. 'It's possible that you have Parkinson's' and I said 'I think I do'. She did a test and was telling me 'did anyone tell you, you are a handsome man'? I said 'no, not lately'. She goes 'you have Parkinson's disease', walked out of the room, and never came back. I was waiting there, I figured she was going to come back and see me and nope, they said that's it – that was it. -P12(3)*

In both situations it resulted in participants getting the care they needed and in Peter's case it led him to getting diagnosed after seeing 27 specialists and 10 years of not knowing what was wrong.

Patients can play varying roles regarding their health whether it is the patient who does not see a physician most of their life but feel by a certain age they should, the

patient who is in complete control of their appointment, or the person who does not take responsibility for their health and it becomes the physician's fault. Regardless of the experience, all participants' emphasized the impact of communication. If there is not active communication it results in patients purposely not adhering to their medications or following their physicians' recommendations because they are unable to understand the need for the medications and do not place value in what is said because of their perceptions of their physician. These perceptions can often interfere with the person's overall views of the health care system.

### **Canada's Health Care System**

As already outlined to some degree under patient – physician communication, participants' decisions regarding their medication is multi-faceted. Participants spoke specifically of the challenges with Canada's health care system and not receiving the care when needed. A select few spoke of positive experiences; however, this was often related to direct communication with a health care professional. Barriers to the health care system have impacted the decisions individuals are making regarding their health.

#### *Barriers and facilitators to care:*

Participants were asked about their experiences regarding the health care system. Some asked for further elaboration and they were asked to share some of the barriers and/or facilitators they have experienced in relation to Canada's health care system. Very few touched upon any positive experiences they have had with the system besides direct patient-physician contact. A barrier that was expressed by Mikaela was also supported by her physician and how taking one medication off the market drastically changed so many lives.



*I was on great medication, well you've probably heard of Vioxx, which they took off the market which is the stupidest thing they ever did. And now people are, my doctor says kids are in wheelchairs that walked. People are crippled that could move and it was an amazing drug. It did wonders for me too; I was like a totally different person. -P10(2)*

It was interesting that a question about the system resulted in touching upon the effects of the pharmaceutical industry and the TPD's role in taking a certain drug off the market.

This experience caused the person to have to take numerous other medications to determine another treatment that was just as effective as Vioxx, which led the person to experience numerous setbacks because of the trial and error process associated with taking other medications.

Even when seeking basic care, some felt they were being 'scammed' by the system so made decisions without the benefit of a physician because they would have to wait hours in a waiting room to see their physician for a one minute procedure.

*Ya and I don't like it, I really don't. I think it's a bit of a scam myself. You know try to get in to see them 2 months down the road. You know they're getting paid for you whether you come or not, so who benefits from this? - P10(7)*

*So I don't absorb anything from food anymore so I give myself a shot. The doctor used to do it but I didn't like waiting there for a couple of hours. So I said hell with that give it to me. -P10(9)*

In some capacity all participants recognized the faults with Canada's current health care system – there was almost no possibility of receiving care when needed or individuals where limited in the type of care they received, which was not enough to help them manage their condition.

The participants in this study all had a chronic condition (often multiple conditions), reflecting a group of individuals who rely on the services of Canada's health care system. Unfortunately, participants spoke of feeling limited because of the barriers

in Canada's health care system and have had to factor these limitations into their decisions regarding their own health, often requiring individuals to make sacrifices. This will be expanded upon in future implications.

### **Chapter 5: Discussion**

The purpose of this study was to develop a theory on the process of decision-making regarding medication adherence in individuals between the ages of 40 to 55, who were required to take three or more prescribed medications, and were diagnosed with a chronic condition. Medication adherence can be defined as the ability of an individual to coincide with medical advice (Golay, 2011; Kaufman & Birks, 2009; McDonald *et al.*, 2002). For the purpose of this study, this definition was used as basis for determining if participants' engaged in adherence behaviours. Using purposive sampling strategy, 15 individuals were interviewed who met the inclusion criteria with the researcher collecting additional information on the person's occupation and employment status, as after the first interview this was recognized as a factor affecting medication adherence. Results were analyzed using the methods of constructivist grounded theory with a cognitive awareness of the theoretical framework, symbolic interactionism. Throughout the research process an interpretative and subjective perspective was utilized as a means to have a central focus on participants' experiences and maintaining their voice throughout the results.

The main themes in the literature included: the costs of health care, individuality, patient – physician communication, and Canada's health care system. The themes from the literature were only considered as single factors and not as co-existing factors. Based on participants' experiences predominant themes and categories emerged with a core

theme of ‘balance of medications with the rest of the person’s life and the meanings individuals associated with their medications’ becoming the centralized theme. Other subthemes included: sense of security, inability to function, sacrifices, rationalizing non-adherence, fear, and active communication with their physician. It was evident the interconnection of the subthemes. For example, some purposely engaged in self-management strategies while others spoke of the need to do so but made ‘excuses’ for not doing more for their health; however this did not predict medication adherence behaviours. Medication was sacrificed because of expenses and individuals placed more value in providing for others than themselves. This resulted in participants recognizing the challenges of not being able to take their medication yet the need for their medications to perform everyday tasks. Even when participants were able to afford their medication and recognized the need for it, this did not equate to adherence. For some, dependency on their medications resulted in ‘playing’ with their medications, with the person deciding on their doses despite their prescriber’s recommendations.

Participants who chose to ‘play’ with their medications, who purposely sacrificed their health, and those who recognized their dependency on their medications to function, resulted in almost all participants having feelings of fear. This included fear of the unknown and of not being able to control their condition even with prescribed medications. Adherence to medications became a contradiction; all participants recognized the need for it yet also recognized that their medications could only do so much for their health and engaged in non-adherence, resulting in no sense of security. For some, in attempt to feel secure, participants engaged in self-management strategies.

Wagner and colleagues (2005) suggested that self-management was an active process that requires patients to make day-to-day decisions to manage their medical condition(s) and that these decisions play a vital role in managing chronic conditions. The effectiveness and quality of integrating self-management strategies into one's life is a strong determinant of health outcomes (Wagner *et al.*, 2005). This study supported these results but also had some contradictory findings. Some participants recognized how engaging in self-management strategies contributed to their health. This involved staying active, monitoring what they ate, and engaging in relaxation methods. In some instances participants spoke of wanting to do more, however, due to financial limitations were unable to afford additional self-management strategies. Participants recognized how engagement in self-management strategies reaffirmed to some extent that there was not a reliance on medications and medication only aided their management of their condition to a point since there was value in engaging in other strategies.

Participants found it was challenging to maintain a balance with their life and their medications. These individuals contradicted themselves because they were aware of what they had to do in terms of self-management strategies yet labeled themselves as a 'failure' for being on multiple medications. However, they were purposely not engaging in any other form of self-management. This mentality of wanting to do more but choosing not to was very common among those who felt their condition was predisposed (i.e. genetic) and viewed their medications as 'inevitable'. This placed less value in self-management as individuals did not attribute their health outcomes to not engaging in self-management strategies, which was not consistent with the literature.

Some participants engaged in self-management strategies by making the additional effort to educate themselves on their condition(s) and medications. This increased their ability to justify and understand the purpose of their medications, yet even with this increased knowledge, this did not predict medication adherence. Unlike the literature that concluded that those with a chronic condition purposely limited their search for information about their condition because he/she did not want to identify themselves as an 'ill' person (Auduly *et al.*, 2012; Kralik, 2002; Townsend *et al.*, 2003), this study found that participants conducted their own research about their conditions and found strategies on their own that they could use to help manage their condition beyond taking medications. However, even with the increased knowledge around self-management strategies, this did not always equate to individuals taking action, reaffirming the complexity of this group of individuals.

Participants also engaged in self-management strategies through support of others. The literature shows that chronic conditions place a different set of demands on a patient than does an acute condition – chronic conditions require continual decision-making and adjustments to changing circumstances for both the patient and loved ones (Ledford *et al.*, 2010; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). This study found that participants who had additional support were more likely to have a drug regimen in place and engage in self-management strategies because by having the additional support there was an emphasis placed on adherence for functionality. That is, they wanted to be healthier not just for themselves, but to support and help others as well. Not all participants had the option of support. This study found that for those who did not have any form of support spoke of the importance of having to rely on themselves yet those who had support, were

not more likely to adhere their medications. The meanings of medications did not vary from those with no support versus those with supportive relationships.

The results found that participants purposely engaged in self-management in an attempt to maintain their privacy, which was often reflected in one's ability to continue to work. The literature suggests that men face identity dilemmas such as preserving a public persona (i.e. maintaining their privacy) (Charmaz, 1994). The findings of this study found that preserving a 'public persona' was not limited to males. Regardless of gender, maintaining privacy was highly important to all participants and no one wanted to appear 'ill'. The ability to maintain a 'public persona' was an indication that the person was able to manage their condition with prescribed medications and could keep the need for multiple medications from their employers, achieving a level of privacy that they could not achieve at home. Individuals were more likely to adhere to their medications if they wanted to maintain their privacy (primarily related to the workplace) to allow individuals to 'function' and maintain their life. Not all placed importance in maintaining their life (directly related to medications) and were purposely sacrificing their prescribed medications.

Sacrificing medications was justified due to financial limitations, for others, and for personal reasons. Participants spoke of purposely limiting their adherence because of the costs of their medications. This study found that the majority of participants were fortunate enough to have coverage through their own plan or in combination with their partner's plan. However, some were forced to evaluate the effectiveness of their medications because of affordability and limitations with their coverage. Consistent with the literature, those who did not have any form of prescription coverage and with a lower

household income were more likely than those with health coverage to report cost related non-adherence (Golay, 2011; Kennedy & Morgan, 2006; Law *et al.*, 2012; Schoen *et al.*, 2007; Schoen *et al.*, 2010). This study found that even with some form of prescription coverage, individuals were citing cost related non-adherence. This was taking place to some extent because provincial drug plans are preventing individuals from taking their prescribed medication (Demers *et al.*, 2008; Grootendorst, 2002; Schoen *et al.*, 2010). Based on the limitations of provincial drug plans, individuals who would benefit from it do not qualify because of their income yet this is not considering the expenses individuals need to live. Those who do qualify for it are sacrificing their medications because paying the deductible on their medication plan becomes less important than being able to provide for their family.

This study also found that individuals who had some form of coverage were purposely limiting their medication adherence to make their medications last longer to provide for others. Individuals recognized their reliance on their medications yet found greater importance in providing for others versus themselves. One may question if this relates to the generation under review who are having to care for their parents, their families, and are placing less precedence on their own health to provide for others. Finally, even with some form of coverage, it was often not enough to cover the price of all of their medications. Almost all participants spoke of having to make out-of-pocket expenses if they engaged in any other form of treatment beyond their medications. Not all were fortunate enough to have the financial means to do so and suffered from not being able to seek alternative care. This resulted in a common emotion in almost all

participants of being fearful of their inability to manage their condition and as a result medication.

A main finding from this study was an underlying feeling of fear that participants had. Fear became associated with participants' medications because of the dependency on their medications, with the realization that even with access to prescribed medications, this still did not improve their functionality. Participants spoke of being fearful of the future because of not knowing what could happen next (i.e. if they lost their medication coverage or if a medication that was once effective no longer worked for them) due to their reliance on their medications. For some, their dependency on their medications was affirmed through experiencing the effects of non-adherence, leading to fearful experiences and their inability to control their lives without their medication. This emotion of fear was not exemplified in the literature in relation to living with a chronic condition and medication adherence behaviours. The results also demonstrated that participants had feelings of fear through comparison of others who were diagnosed with similar conditions.

It should be noted that the term 'dependency' is used in various contexts throughout medication adherence literature. In some contexts, 'dependency' is referring to an addiction to medication (Asmundson, Wright, Norton, & Veloso, 2001) while in other contexts it is used to describe individuals who are dependent on their medications to live, specifically pertaining to those diagnosed with a chronic condition (Ruppar, Dobbels, & Geest, 2012). This research study focused on the foundation of constructivist grounded theory and focused on the words of participants, if participants used the word 'dependency' the researcher presented it in the context used by the participant, with the



objective of maintaining the integrity of the data. In some context the literature indicated that a patient's commitment to their drug regimen was dependent on the patient's beliefs and values including the patient's views of themselves (Auduly *et al.*, 2012). The findings of this study support this to some degree. Participants' views of themselves involved comparing their condition and medication use to others, resulting in feelings of fear because participants were aware of what could happen due to their chronic condition and how a dependency on their medications could result in 'playing' with their medications. Comparison to others did not necessarily affect a patient's commitment to their drug regimen, as many spoke of not following their prescriptions, but comparison to others and knowing of the possibility of what could happen, affected their views of themselves. In some way knowing that others who were similar in age and who were also having to take multiple medications, allowed participants to shift from who they were once were before being prescribed their medications to who they have become as a person taking multiple medications.

While the literature outlined how a patient's values and beliefs influence their commitment to their drug regimen, the literature was unable to provide evidence around how fear can influence a patient's commitment to their drug regimen. Fear was a predominant theme throughout this research study, with participants speculating their future and fearful of how this would affect their ability to adhere to multiple medications. Participants exemplified the complexity of their adherence behaviours and already spoke of the struggles even with provisions in place to help them succeed with medication adherence (i.e. medication coverage) yet there was still this worry of the fear of the future and adherence. However, in very few instances fear of the future was a motivator for

adherence, when this did take place it was often in an attempt to try to be on fewer medications over time. This was not consistent among participants and even with individuals speculating of the fear of their future, many spoke of experiences of non-adherence as well as seeing themselves on more medications over time as to them their chronic condition(s) and medications were viewed as 'inevitable'. Once again, this demonstrates the complexity of this group in making decisions regarding their medication choices and how living with a chronic condition, often multiple chronic conditions, places a massive demand on individuals, requiring individuals to engage in various methods of long term decision-making.

The literature on individuals with a chronic condition searching for normality outlined the loss of control individuals with a chronic condition feel over life circumstances and the need to retain their previous identity (Asbring, 2001; Charmaz, 1994; Kralik, 2002). This was consistent with the current study's findings. All participants spoke of the importance of being in control yet there were feelings of the loss of control, which happened due to individuals not knowing why they were ill and choosing not to adhere to their medications. Individuals had to rediscover what they were capable of doing and for some they still represented themselves as being 'strong' and 'able to do anything', which was ironic because as interviews progressed, all participants spoke of the continual struggles they have in managing their condition with their medications as this required daily decisions. Experiences of not being able to perform tasks individuals were once capable of doing, caused participants to realize that to attain some aspects of their previous identity, there was a need for their medications in order to live a 'normal' life.

A 'normal' life took on a new definition for participants as a new normal meant having to take medication on a daily basis and being unable to perform tasks the person was once capable of doing. This study found that living with a chronic condition meant individuals taking risks and engaging in daily decisions to adhere or not adhere to their medications. Asbring (2001) and Kralik (2002) found that women were more likely to embrace their medical condition and reconstruct their identity to gain a sense of empowerment and control versus men who struggled with their identity and having a chronic condition. This was not consistent with the study's findings. Almost all participants spoke of the struggles of being on multiple medications at a relatively young age and associated having to take medication as being a 'failure' and being an 'old person'. Participants did attempt to gain some form of control through medication adherence and engaging in self-management strategies yet there was never any sense of security, so there could never be a true sense of control or feelings of empowerment.

Prescribing experiences resulted in variance in what medications meant for participants and impacted their medication adherence decisions. Even when individuals placed an importance on taking their medications, adherence did not always take place; once again highlighting the common theme of individuals contradicting themselves and their decisions. Townsend and colleagues (2003) outlined how prescribed medications play a key role in managing symptoms, allowing individuals to carry out everyday tasks that can become central to one's identity. All participants were aware of the need for their medications to function in everyday life. The literature outlined that other factors do play a key role with patients choosing to adhere or not adhere to multiple medications based on the perceived need of their medications and the effectiveness of their

medication (Kreps *et al.*, 2011; Ledford *et al.*, 2010; Lewis *et al.*, 2003; Townsend *et al.*, 2003; Zhao *et al.*, 2011). This study was consistent with the literature and found that participants were purposely not adhering to their medications because they did not understand why they had to take certain medication(s) or thought they were in control of their health, so there was no need for their medication(s). Individuals then rationalized their non-adherent behaviours, as they were consciously making the decision to not adhere versus simply forgetting to take their medications.

The literature also outlined that non-adherence was due to experiences associated with the side-effects of medications (Kreps *et al.*, 2011; Ledford *et al.*, 2010). The results support this to some extent. Some participants purposely spoke of not adhering to their medications because they could not deal with the medication side-effects. However, some spoke of the side-effects that have limited their ability to function and live a 'normal' life yet still had a dependency and a reliance on their medications because the side-effects were more manageable than without their medications. This could be contributed to the ability of the prescriber to communicate the effectiveness of the patient's medications.

The literature on patient-physician communication has found that patients are at a greater risk for non-adherence if they have minimal interactions with their physician (Kennedy & Morgan, 2006). High quality and cost-effective treatments would be best achieved if there was a partnership between the patient and the health care provider (Kaufman & Brinks, 2003). This was consistent with the study's findings. Participants placed an importance on the quality of care they have received from their health care providers and that there was value placed in their role as a patient. The majority of

participants had a very proactive approach to their health and had no issues voicing their concerns with their physicians; however, some interactions with their physician led to non-adherence. This was consistent with Nair and colleague's (2008) study that concluded that non-adherence was attributed to the patient not receiving enough information about their medications and could not make an informed treatment decision. All participants spoke of the importance of making informed treatment decisions, which was not always reflected in participants' final decisions. Participants in the current study took the necessary steps to become informed about their condition and medications, as many participants needed justification as to why they were on medications at a relatively young age. Thus, there could be a significant age effect that future research should explore as more and more young adults are being prescribed chronic medications for the rest of their lives.

The literature outlined the need for healthcare providers to focus on patient-centred care, which is characterized by promoting a better understanding of the patient's life, empowering patients, and tailoring treatment to the patient's needs and preferences (Golay, 2011; Tinetti *et al.*, 2004; Wagner *et al.*, 2005). This study found that this is highly important for physicians to do. One participant highlighted that she did not want to see her specialist or follow her specialist's recommendations because the prescribed treatment did not consider her values and beliefs and her concerns were often dismissed. Physicians that have played an active role and have addressed patients' concerns have had better health outcomes (Wagner *et al.*, 2005). This finding was also consistent with the study. Majority of participants did play a very active role in their health but participants who had health related goals (typically to be on less medications by a certain

age), spoke of the continual support from their physician. Through physician support and participants having active communication with their physician; this affected individuals' decision-making process, with individuals then more likely to share with their physician their choices related to adherence. The results exemplified that patient-physician engagement can be very difficult as this age bracket does not have a need to see their physician unless identified need by the patient or for screening at the age of 50. This becomes a challenge for a physician to develop a relationship and determine if adherence is taking place, which is also impacted if the patient is seeing numerous health care professionals and being prescribed medications from different sources.

The literature outlined typical barriers to the health care system, which included: long wait times, being unable to see a physician the same day care was needed, difficulties in scheduling appointments, contacting their physician via telephone, and getting prescriptions refilled (Ledford *et al.*, 2010; Schoen *et al.*, 2010). The issue of 'time' was a consistent finding throughout the study. This resulted in patients purposely not making an appointment with their physician despite needing care because by the time they got an appointment they would forget why they made it to begin with. In one instance, long wait times resulted in one participant giving herself a needle every 2 weeks when her physician was technically required to do so. There were also long wait times to see specialists when participants were in a moment of crisis and needed someone to talk to. This meant individuals having to rely on their family physician for this type of care because by the time they would be able to speak to a specialist, the moment of crisis would have already lapsed. Some individuals were fortunate enough that they could contact their family physician on demand but this only was available to very few

participants. Thus, the main barrier to the healthcare system, and consistent with the literature, was time. One may question if this barrier of time could be addressed if patients were more aware of community resources to address their needs and if patients had a realistic expectation of what they are asking of their health care professionals; this will be consider in greater detail under future implications.

### **Strengths and Limitations:**

One of the main limitations of this study was conducting only a single interview with each participant focusing on one point in time. According to Charmaz (1990) given the nature of living with a chronic condition, multiple interviews are necessary to get through the basic information of the course of his or her health experiences. By conducting multiple interviews it may have contributed to the participant's level of trustworthiness that was placed in the researcher. Furthermore, by having multiple interviews over a longer period of time, this would have been beneficial to document the potential changes in participants' adherence behaviours and if their meanings associated with their medications changed over time. However, even with a single interview it was evident throughout the interview process that as interviews progressed and participants were able to get comfortable with the researcher, a certain depth of information was shared. In many grounded theory studies, only a single interview is possible, but the studies are still considered robust and trustworthy (Creswell *et al.*, 2007; Holstein & Gubrium, 2003; Schou & Hewison, 1998). Participants did focus on the progression of their experiences, often rationalizing who they had become in relation to their medications and chronic conditions. The literature suggests this is evidence of a valid, stable interview process (Corbin & Strauss, 2008; Patton, 2002; Strauss & Corbin, 1990).

Finally, participants were aware that there was only a single interview taking place, which could be speculated as to why a certain depth of information was shared with the researcher.

After conducting the initial interview, the interview guide was altered for the remaining interviews. Based on the methodology of constructivist grounded theory, the researcher is encouraged to add areas to further pursue and delete questions that do not add value to the overall project, with the intention of collecting data that was missed during the initial interviews (Charmaz, 1995; Creswell *et al.*, 2007; Holstein & Gubrium, 2003). However, this was only possible with participants that were interviewed later in the process since the researcher did not have the opportunity to conduct multiple interviews and pursue areas that could have been further elaborated on. Although later interviews benefited from what was learned, the original interviews may have lacked some depth and focus.

Another limitation was the researcher's inexperience with grounded theory interviewing. This was her first experience conducting interviews. The researcher piloted the interview guide with family and friends. It should be noted that the interview guide was not piloted on individuals who met the inclusion and exclusion criteria as it was immediately recognized the challenge in recruiting individuals who met all of the requirements of the inclusion and exclusion criteria (refer to Appendix B). For the purpose of this research study, piloting the interview guide with five individuals allowed the researcher to practice the art of interviewing, focusing on conversation as opposed to following the guide word by word. The researcher was aware of having only a single opportunity to interview participants and wanted to ensure that key questions were



included that allowed participants to speak to their experiences regarding their own health. The interviewer also received significant training from Dr. Cosby, and was guided through a comprehensive list of readings from the qualitative literature by her supervisor. However, even with piloting the interview guide, this is still not adequate preparation for what is needed for qualitative, in-depth interviews. Charmaz (1990) touched upon a key limitation within this study that the quality of data earlier in the process differed from the later interviews because of the time it took to develop the confidence and skills in conducting interviews. The researcher had to find a balance of not asking direct questions because of the comfort level of participants. It took time for the researcher's skills to develop and have an awareness of techniques that worked best in conducting interviews that were asking individuals to share very personal details of their life.

There were also challenges associated with collecting the sample required for the study. The researcher found it difficult to recruit participants who met the age bracket of 40 to 50. This resulted in altering the sample criteria's age requirement to 40 to 55. In reality, by increasing the age bracket there was no dramatic difference in the variance of experiences of someone who was 40 versus someone who was 55. The majority of participants were at similar stages in their lives and this did not appear to alter the data by changing the age group. A strength of this research study was the focus around the 'sandwich generation' (Do, Cohden, & Brown, 2014; Hammer & Neal, 2008; Hansen & Slagsvold, 2014; Townsend *et al.*, 2003). The sandwich generation is a very unique group who are more concerned with caring for others than themselves despite the posing threats to their health (Do *et al.*, 2014; Hammer & Neal, 2008; Hansen & Slagsvold,

2014; Townsend *et al.*, 2003). Further investigation is needed around this age bracket to explore in-depth adherence factors outlined by participants (i.e. self-management, sacrificing medication, fear, and patient communication with health care professionals) as it still not fully understood the complexity of the decisions for those between the ages of 40 to 55.

A potential limitation of this study is the sample size, which consisted of 15 participants. A common misconception about sampling in qualitative research is that sample sizes that are too small are unable to support the claim of having achieved theoretical saturation (O'Reily & Parker, 2013; Sandelowski, 1995). In qualitative research, there is no set number of participants; the sample size is reached when data is saturated and there are no new emerging themes or categories (Corbin & Strauss, 2008; Creswell *et al.*, 2007; O'Reily & Parker, 2013; Patton, 1980; Sandelowski, 1995). Based on the purpose of this research project, there were no new emerging themes or categories after 15 participants were interviewed, and the data was saturated with evidence. To further iterate this, according to Strauss and Corbin (1990) theoretical sampling can be defined as: "If numbers are important for satisfying a committee, or oneself, then instances of occurrence of phenomena can certainly be counted" (p.191). In other words, in grounded theory, the concern is not with the number of participants, but whether or not each participant experienced the phenomena. In the current research study, each participant was consuming multiple medications and was able to explicate numerous important experiences with the said phenomena under study.

Taking into account the sample size, a potential limitation is the explication of divergent and convergent themes. With any qualitative research project, there is always a

concern with how to handle data that is not consistent with overarching themes. Patton (1990) strongly urges that you seek out discriminate or divergent data to challenge the development of your categories and themes. Strauss and Corbin (1990) suggest, ‘the flip-flop technique’ be used to enhance one’s ability to find those pieces of data that negotiate or require significant changes to thematic development. Strauss and Corbin (1990) further suggest this technique enhances overall theoretical sensitivity in grounded theory. In the current study, divergent data was reviewed, using these techniques to enhance theoretical sensitivity. When this data was reviewed by both investigators, the remaining divergent data was determined to be insufficient to alter the final themes and categories of the grounded theory. The final technique used was a systematic comparison (Strauss & Corbin, 1990), were one breaks away from custom forms of thinking. This further sensitizes the researcher to speak out and attempt to incorporate all divergent data into the grounded theory. Therefore, although some divergent data could not be included in the grounded theory, every possible mean was utilized to do so.

Despite having an adequate sample size and reviewing the divergent data, a limitation of the study was the methods utilized to recruit participants. Participants were recruited through a primary care office in Niagara, a physiotherapy clinic in Halton, Niagara Region Public Health, and through word of mouth by the researcher. A challenge with this method is that individuals are being recruited who are more likely to have access to health care than the average population, and are more likely to have medication coverage as well as having the means to afford additional treatment (i.e. physiotherapy). This is not to say that participants in this study all had those luxuries but it is recognizing that future research should be considering other methods that are

representative of adults who are on multiple medications, who are still utilizing the health care system, but may not necessarily have a family physician. Future research should consider recruiting in public places to ensure there is representation of the targeted sample.

## **Chapter 6: Conclusion**

Schou and Hewison (1998) outline how different explanations of health and illness may be experienced by the same people in different ways depending on the situation. This piece of literature encompasses this research project perfectly. This project aimed to answer the questions: what factors influenced individuals decision to adhere to a drug regimen? How do specific factors affect the person's ability to adhere or not adhere to their prescribed drug regimen? Based on individuals willingness to share their experiences, it was apparent how multifaceted living with a chronic condition can be and the number of factors that impact individual's ability to adhere or not adhere to their prescribed medications. A core theme emerged in participants' experiences that those with a chronic condition who are relatively young, associated meanings with their medications and this impacted their decisions to 'live' their life according to their medications.

Individuals spoke of the challenges of balancing their medications within the context of their life. Some spoke of engaging in self-management strategies because there was value in wanting to do more for their health. This included educating themselves on their conditions and their medications, as many spoke of not knowing the need for their medications. Individuals also spoke of the value of others supporting them in self-management strategies and how this positively affected their ability to control

their condition and as a result medication. However, all participants recognized the need to engage in self-management strategies but some were purposely choosing not to, often because they saw their medications as ‘inevitable’. This was ironic because having to take multiple medications led individuals to view themselves as a ‘failure’ and having feelings of being disappointed as to whom they had become. Regardless of engagement in self-management strategies, this minimally affected individuals’ ability to adhere to their medications. The evidence suggest to some extent that those who placed blame on themselves for their condition, were the most likely to adhere to their medications as having to take prescribed medications became their fault. Thus, to some extent there was more value in adherence.

Not all placed value in their medications and medications were sacrificed. Individuals spoke of purposely not adhering to their medications due to the restrictions of cost. Many recognized they had other costs in their lives and they had to outweigh the benefits of being to afford their medications or being able to provide for their family. This meant individuals sacrificing their health for others. Some participants were fortunate enough to have health care coverage; however, this was often not enough. This meant for some having to live below the poverty line in order to qualify for provincial drug plans or having to decide what medications were more important. Many participants spoke of the out-of-pocket payments they made to seek additional help, such as counselling, which not all could afford despite participants recognizing the serious need for this additional help. If counselling became part of health care coverage, for many this would have made a dramatic difference in helping them manage their condition and possibly resulted in better management of their medications. Living with a chronic

condition is not something that is short-term and by not being able to afford the needed medications or treatments – the stress placed on the person is detrimental.

Individuals recognized that being on multiple medications, meant having to make decisions on a daily basis. This resonated with feelings of fear because there was never any sense of security of the decisions they were making. Individuals were fearful of the future because of the dependency on their medications yet even with a dependency this did not equal functionality. With many participants sharing experiences of having to limit what they chose to do because of the effects of their medications. In some instances, this was a form of rationalizing non-adherence. Having feelings of fear also took place when individuals compared their condition and medications to others. Individuals became aware of what could happen due to their condition and even with this awareness, individuals were still struggling to manage their medications.

Being diagnosed with a chronic condition, often multiple conditions over time, and having to take multiple medications became associated with who the person was. Individuals spoke of the moment they were diagnosed with their condition, having feelings of sadness, anger, and some in disbelief that they were diagnosed with a chronic condition. Being diagnosed with a chronic condition meant having to be on multiple medications, which for some reflected their inability to manage their life and failing to some extent. Individuals recognized they had no choice but to shift to a ‘new normal’. This was very multi-faceted as some recognized a new normal in incorporating their medications into their daily routine and all spoke of attempting to maintain who they once were. However, this was not without its’ limitations as many had to rely on others to perform tasks they were once capable of doing as medications only helped managed

their condition to a point. Individuals had to find strategies to balance who they once were with who they have become, with their medications playing a central role in their lives despite some being unable to accept this fact.

It became challenging for individuals to recognize that there was a need to take their medications in order to live their lives. All participants said they adhered to their drug regimen but as interviews progressed, all participants contradicted themselves and spoke of experiences with non-adherence. These experiences reaffirmed individuals need for their medications as these experiences resulted in severe consequences as individuals spoke of losing complete control of their lives. However, it became a contradiction, in some participants recognizing that their medications were designed to help them yet due to the side-effects of their medications, it resulted in severe setbacks. Medications then became a risk because once again there was never any sense of security and individuals did not want to re-experience the severe side-effects of their medications. For some, this was why they were choosing not to take their medications according to their prescription but a select few still continued to take their medications despite 'being a write off' and having limitations.

This could be related to the ability of physicians to communicate the effectiveness of the prescribed medications, and in some instances that the benefits outweigh the risks. Participants spoke of their relationship with their physician and the importance of having a role in their own health. Participants wanted to know about their condition and medications and be provided with additional treatment options besides prescribed medications. However, not all participants had active communication with their physician. This caused participants to devalue what their physician was recommending

and as a result going against their physician's recommendation, often leading to non-adherence or in two cases deciding to take a medication despite both participants' physicians strongly recommending against it. By having the person contribute to the decision-making process regarding their own health with their physician, this to some extent impacted individuals' decisions to adhere to their medications.

Finally, all participants spoke of the barriers with the healthcare system. This involved individuals not being able to see their physician when care was needed, having to wait in their physician's office for long periods of time leading to feelings of frustrations, and the system not providing better mental health care. Very few participants touched upon the strengths with Canada's health care system and it leads one to question, if individuals received the care they needed, would their health be improved? This meant for many, receiving care that was holistic in nature that did not only address their physical symptoms but considered the overall impact of having to live with a chronic condition.

Living with a chronic condition and having to take multiple medications is a challenging idea for those between the ages of 40 to 55. This age bracket specifically spoke of the challenges of having to take multiple medications at a relatively young age and then how this impacted their views of themselves. Individuals' medications started to having meaning as this allowed individuals to live their life, however, there was recognition that living one's life meant having limitations and shifting to a 'new normal'. Prescribed medications did not become the 'magic bullet' for participants and there was never any sense of security as participants did not always have confidence in their prescribed medications. This impacted individuals' decisions to live their life with some



purposely choosing not to adhere to their medication. There is not one single answer as to why participants chose not to adhere to their medications. This study provided evidence in how multifaceted individuals, who are between the ages of 40 to 55 and prescribed multiple medications, who are making very different choices pertaining to their health.

### **Future Implications:**

Living with a chronic condition and adhering to multiple medications is very complex. From the patient viewpoint, it becomes a challenge for patients to communicate if adherence is taking place when they are talking to their caregivers, especially the age bracket targeted for this research study who have different priorities and technically have no basis for seeing their physician unless for an emergency or for screening requirements based on their age. The results of this study revealed the impact a family physician can have on the patient's ability to adhere to their medication yet this study was not able to provide sufficient evidence in determining the impact of other health care professionals (i.e. specialists) who are also prescribing medications.

The findings of this study also suggest that patients may be continuing to consume medications that are no longer medically needed, and may also be harmful psychologically to a patient. Participants in this study spoke of being on numerous medications and as a result, labelled themselves as a failure – this could potentially be minimized by caregivers reducing the number of medications prescribed to a patient. Our study found that even one less medication can lead to a true sense of empowerment. This could take place if a strategy were employed where an information platform was utilized that allowed health care professionals to store information regarding their patients, specifically around their prescribed medications and the purpose of their medications, and

this platform would permit other health care professionals to review the information as well as enter their information regarding the patient (Sellors *et al.*, 2003). This could benefit health care professionals in improving prescription practices as well as providing a more comprehensive understanding of the needs of their patients, as patients are not always transparent about their health with all of the health care professionals they are seeing (Golay, 2011; McDonald *et al.*, 2002; Osterberg & Blaschke, 2005; Wagner *et al.*, 2005).

With a focus on relationship building between the patient and physician, there should be an awareness of adherence in relation to the diagnosed condition(s) (M. Greenway, personal communication, June 16, 2014). Relationship building may not be feasible for the patient who is diagnosed with a condition that is acute versus a patient with a condition who is routinely required to see their physician to monitor their chronic health condition(s) (Auduly *et al.*, 2012; Gibson *et al.*, 2005; Ledford *et al.*, 2010; Osterberg & Blaschke, 2005; Tinetti *et al.*, 2004; Zhao *et al.*, 2011). Relationships may also vary for individuals who are required to pick up their prescriptions from the same local pharmacist, who have an understanding of the patient's individual needs and are able to provide guidance because the pharmacist also has active communication with the primary prescriber (Austin *et al.*, 2005; Dolovich *et al.*, 2008; Dolovich, 2012; Farrell *et al.*, 2008; Kennie & Dolovich, 2008; M. Greenway, personal communication, July 8, 2014; Pottie *et al.*, 2009). Some research even suggests that a trained pharmacist versus a pharmacist technician enhances adherence behaviours (Dolovich, 2012; Lau, Dolovich, & Austin, 2007). Unlike a pharmacist technician, a trained pharmacist would be able to provide the patient with additional knowledge around their medications, and as this study

exemplified, individuals want to be educated about their prescription medications, which could then potentially influence their adherence behaviours. Based on the misperceptions of medications that participants stated in this research study, patients appear to require additional education and support, which could be provided through a pharmacist who is able to understand the needs of the individual.

This study suggests that to maintain active communication between a patient and health care professional, this may involve addressing health care professionals' prescribing practices. If less refills are provided to the patient, this would leave the patient no other choice but to see their physician to get a prescription refilled more often, resulting in also addressing adherence because there is less time in between appointments and more opportunity to address the concerns and commitments of the patient around their medication behaviours (Holbrook *et al.*, 2011; Holbrook *et al.*, 2012; Holbrook, Goldsmith, & Leung, 2008; Kreps *et al.*, 2011; Randolph *et al.*, 2008). This may be a challenge for individuals who are citing cost-related non-adherence, as having one's prescription refilled more often would equate to an increase in the number of copayments. However, as expressed by participants in this study, when active communication with one's local pharmacist and/or family physician is needed, it may be essential to have copayment fees waived or patients being offered drug samples, although some research suggests providing free samples can do more harm than good (Chimonas & Kassirer, 2009; Cosby & Houlden, 1996; Katz, Reid, & Chran, 2014; Limcangco, Stuart, & Briesacher, 2013; Reid, Alikhan, & Brodell, 2012). Participants from this study were fortunate enough to have positive experiences with free samples, but it required them to be transparent with their local pharmacist and family physician to have their

individual needs met. With that being said, this may become a routine question in that family physicians should begin asking their patients if they can afford their medications and documenting this as part of the patient's record. If this is immediately addressed then patients can be provided with the necessary resources and supports to prevent non-adherence earlier in the process by determining what is needed for the person to be able to afford their medications and possible other non-medication treatments.

To further address adherence behaviours, there may be value in conversations between a patient and health care professional around patient expectations (Miller & Rollnick, 2002; Rollnick, Mason, & Butler, 1999; Rollnick *et al.*, 2010). The results of this study demonstrated how time was a barrier for many to health care, leading to negative preconceptions of the health care system and indirectly affecting patient adherence choices. There is value in future research investigating how patient expectations impact adherence behaviours as well as education for future family physicians in understanding the need to address patient expectations as a basis for addressing adherence behaviours.

It may also benefit individuals who are living with a chronic condition and are prescribed multiple medications to address their own expectations of their health. The results of this study exemplified how participants were comparing themselves to others, typically comparing to worst case scenarios. There may be a benefit for patients who are relatively young and are diagnosed with a chronic condition to meet individuals who have done more to manage their condition and as a result are on fewer medications, as this was recognized by many as being a personal goal. This was an interesting finding and exemplifies how the group selected for this research study are highly influenced by

others, specifically others who they can relate to. By providing them with best case scenarios regarding their health, this may be a motivator in adherence to medication and self-management strategies.

This study also found that family physicians should be documenting if their patients are engaging in non-medication strategies to manage their condition. This could provide family physicians with the opportunity to determine realistic strategies that their patients could utilize besides medications. As this study exemplified, individuals are interested in self-management strategies but are not engaging in them. If this is encouraged by someone who is a trusted source (i.e. family physician) it may result in an increase in self-management strategies, which has been demonstrated in the literature to result in an increase in adherence behaviours.

Finally, participants also had expectations of how long they would be on their medications for, with many assuming that they would be on their medications for potentially the rest of their lives. The evidence from the current study has shown that it becomes important for prescribers to have conversations around this expectation as this would be an opportunity for the prescriber to address this unrealistic expectation, provide other strategies besides prescription medications, and to educate patients that over time they may gradually be on less prescription medications – once again providing the patient with options and supporting their role in their own health.

Due to the focus on chronic conditions in this study the majority of participants were being prescribed medications for primary prevention. Future research is needed to determine if adherence behaviours vary for someone who is on a medication for preventative purposes versus someone who is on medication for reactive purposes. One

may speculate that medications used for secondary prevention would result in greater adherence behaviour, as the benefits of being on these types of medications are more tangible and do not require individuals to adhere to medications over a longer period of time. As this study exemplified, individuals' chose to not always adhere to their medications that did not provide immediate, tangible results as participants assumed that certain medications were only intended for short-term use. However, in reality these medications were prescribed as a preventative method, which entailed the person having to adhere to their medication for a longer period of time.

Based on the outlined implications, a key recommendation proposed would be for policy makers to take into account this age group who are being prescribed multiple medications at a relatively young age. By addressing the unique health needs of this age group, it would result in economical savings as fewer health care resources are then being utilized by this group. However, for this to take place, changes need to be made. First, there needs to be consideration of the costs of medications. Individuals are purposely sacrificing their health because they are unable to afford their medications. These individuals are making slightly more than \$20 000 per year so are not qualifying for the Ontario drug savings plan yet when one takes into account the additional expenses in these individuals' lives, they are in fact making significantly less than \$20 000. Second, it was apparent how influential peers can be for this group in not only adhering to their medications but engaging in self-management strategies. As previously outlined, this group often relates to individuals who are in the worst case scenario. With that being said, there may be a benefit to provide funding to chronic disease organizations that can provide peer support groups to allow individuals who are experiencing similar conditions

to discuss methods they are using to manage their condition(s) as well as their medications. However, for this to be successful it needs to be promoted as a ‘prescription’.

All participants spoke of viewing their family physician as a trusted source – this must be capitalized on. A first step could be providing family physicians with the resources that they can then ‘prescribe’ to their patients to seek additional treatments besides their medication, with the physician purposely following up with their patient to determine if they followed their recommendations. This would hold the family physician accountable to make an appointment with their patients to follow-up on the preventative strategies being recommended and to focus on relationship building between the patient and the physician. There also becomes an opportunity for family physicians to start documenting the ability of their patients to afford their medications, determine if they are engaging in self-management strategies, and if they are being prescribed medications. By family physicians documenting this, possibly included as part of their EMR, then there becomes a more comprehensive approach to health as individuals in the current study were citing numerous and often complex reasons for non-adherence (Holbrook *et al.*, 2011a; Holbrook *et al.*, 2011b) . If policy is not possible, there still needs to be a focus on small changes, whether it is the patient who is able to have copayments waived or who has a family physician that addresses preventative methods; these are the potential opportunities with the results of this study.

### **Summary Conclusions**

This study found that individuals living with a chronic condition (often more than one) and who are required to take multiple medications have a very complex relationship

with their medications and consequently with their care providers, loved ones, and the health care system. This research was able to identify that adhering to one's medications are very multifaceted and there are certain factors that are influencing individual's conscious decisions to adhere or not adhere to their prescribed drug regimen. Individuals are purposely sacrificing their medication by placing less merit in their own health and more merit to support others. Even with an awareness of the need of their medications to function, this still does not equate to adherence. This group requires increased education and support as individuals spoke of non-adherence because there was not a recognized need for their medications and the results of their medications were not 'tangible'. If the importance of medications was discussed between the patient and the prescriber, it may minimize the feelings of fear.

This study found that many multi-medication users are fearful of having to be on multiple medications, often believing that it will only get worse with age, resulting in feelings of fear of the future. This is the expectation that many have of themselves yet this is a group of individuals who recognize that they are relatively young to be on multiple medications. There becomes a contradiction when expectations are not matching with participants' personal experiences. Prescribers are in an interesting position to address patients' expectations, possibly helping the patient devise realistic expectations and provide the person with the hope of being on fewer medications over time.

However, this also requires the prescriber to address self-management strategies. While this study found that very few engaged in self-management, but those individuals who did were more likely to adhere to their medications. The majority of participants



had an awareness of wanting to do more for their health but purposely chose not to. By engaging in self-management strategies this may address the challenges this group is experiencing with regards to being on multiple medications. This research is able to exemplify how individuals associated meanings with their medications and this age group is very unique from most in that they have an awareness of what they need to do but are constantly rationalizing every decision made, reaffirming the importance of increased education and support. For this age group to successfully adhere to their medications there needs to be a balance between living their life and taking their prescribed medication. This study has shown that the use of multiple medications is not a linear process of simply adding more medications consumed each day by an individual. Instead, this study has shown that multiple medication management requires an increased understanding of complex interrelated factors that impact adherence and non-adherence behaviours.

## **Chapter 7: Bibliography**

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## **Chapter 8: Appendices**

### **Appendix A: Semi-structured interview guide**

Tell me a little bit about yourself (icebreaker to start building trust with participants).  
What do you do for a living? If indicate yes, are you full or part time? Tell me about the medications you are currently taking. What health conditions are these medications prescribed for?

<b>Interview Questions</b>	<b>Probe Questions</b>
1. How many of those medications do you take according to the prescription?	Interesting, why is that?
2. If you would like to share with me how you felt when you were first diagnosed with your health condition?	How did this affect how you feel about yourself?
3. How does your condition affect your life?	Depending on the answer, ask participants to consider specifically personal relationships, their workplace, and them as an individual
4. Tell me about any experiences you've had with your medications (i.e., side-effects, benefits, incorporating your drug regimen into your daily routine, etc.).	How has this affected your decision in taking your medications? Do you feel you were able to make an informed decision? If yes→ Why so? If no→ Why not? Has anything else in your life affected your decisions to take your medications or not to take your medications?
5. What steps have you taken to manage your conditions? (i.e., exercise, eating healthy, alternative medicine, etc.).	If you would like to share with me any experiences you've had that have caused you to take these specific steps. Where you recommended any self-management strategies or treatment options by your physician?
6. Tell me about your relationship with your family physician.	If they are seeing more than 1 physician, ask if there is a different relationship with each person.
7. Have you had any difficulties with the healthcare system?	Yes→ Tell me more about it. No→ Why do you think this is?
8. Do you feel you are supported in the decisions you have made?	Why is that?

The questions were based on the sequential steps reflected in Figure 1 that lead a patient to the final decision in their medication adherence. If patients are adhering to their medications, is it because of the patient's ability to self-manage their condition or is it due to other factors that were not outlined in the literature? For patients who choose not to adhere to their medications, the interview will reveal if barriers outlined in the literature (i.e., structural and personal) are consistent with participant experiences. According to Figure 1, patients choose to continue to take their medications based upon the strategies the patient is personally able to implement as well as active communication between the patient and their physician; while patients who choose not to continue to adhere to their medications base this decision on the inability to control their condition(s) and/or poor patient-physician communication.

Figure 1 focuses broadly on the factors affecting medication adherence but Figure 2, 3, and 4 address specific factors participants will be asked to speak about. Figure 2 is reflected in question 4, where participants are asked to share any experiences they've had with their medications; specifically how does their drug regimen affects their life? It will be interesting to see if participants speak of the need to substitute their medications, the choices they are provided with, and if their knowledge and perceptions of their health affect their decisions. Figure 3 is reflected in questions 2 and 3 where participants are asked about how they felt when they were initially diagnosed and how their medical condition has impacted their lives. Figure 3 is also considering the effects of gender. As previously outlined, females were more likely to feel a sense of empowerment when searching for a balance between their multiple conditions and their personal lives, while men were more likely to feel a loss of control because of the fear of being dependent on a



medication for a long period of time and being unable to live a 'normal' life (Asbring, 2001; Charmaz, 1994; Kralik, 2002; Lewis *et al.*, 2003). Finally, Figure 4 considers more in-depth the importance of communication between the patient and physician. This is reflected in questions 6 and 8, which is based on Figure 4 that considers the impact a physician can have on the ability of a patient to adhere to their medication. The questions pertaining to patient-physician communication will aid in supporting the figure, thus the literature, or disapprove what has been said in the literature.

## **Appendix B: Inclusion and exclusion criteria**

### **Inclusion criteria:**

- Participants are between the ages of 40 to 55 when data is being collected
- Male or female
- Diagnosed with a chronic condition; not limited to a single chronic condition
  - According to the Centre for Chronic Disease Control and Prevention in Canada (2010) the most commonly diagnosed chronic conditions in 2010 were heart disease, stroke, cancer, diabetes, and arthritis
- Required to take three or more prescribed medications to manage diagnosed condition(s)
  - However, participants will be asked to indicate if taking any other medications that were not prescribed by their healthcare practitioner or engaging in other treatment options (i.e. alternative medicine)
- There will be no restrictions for health coverage; participants will have to indicate their available health coverage but this will not exclude individuals if one does not have any form of coverage
- Engaged in communication with a physician or specialist that gave recommendations to improve health

### **Exclusion criteria:**

- Under or over the preferred age bracket
- Not diagnosed with a chronic condition
- Prescribed less than 3 medications
- Does not actively engage in communication with a physician pertaining to the participant's personal health

## Appendix C: Summary of research project



April, 2013

Title: 'Multiple medication use in adults: A qualitative study'

The purpose of this research project is to develop a theory of the process of decision-making in medication adherence in adults between the ages of 40 to 55 who are required to take multiple prescribed medications. Specific organizational and individual factors (i.e. the costs of healthcare, individuality, patient- physician communication, and Canada's healthcare system) will be analyzed while investigating the influence these factors has on a patient's ability to follow their physician's recommendations.

Based upon data collection with a focal point around individual experiences it will aid in developing a framework for healthcare providers in understanding the context and the rationale behind a lay person's decisions in adhering to their prescribed medications. Once a rationale has been provided for adherent or non-adherent behaviors, a hierarchy will be created exemplifying what factors are most affecting individuals while considering the demographic of the person.

There is a need for research in understanding the decisions in multiple medication use since over half of prescribed medications for patients with chronic conditions are not taken as prescribed, resulting in health and economical consequences (Golay, 2011; Osterberg & Blaschke, 2005). Furthermore, those between the ages of 40 to 50 are more likely to exhibit non-adherence behaviors due to the costs of medications and personal factors (i.e. not accepting being labelled with a chronic condition) (Auduly *et al.*, 2012; Law *et al.*, 2012). However, research has been unable to exemplify why this specific age bracket is exhibiting non-adherence and what specific factors are causing a patient to take certain medications while choosing not to take others.

To recruit participants we are looking to place advertisements within local pharmacies where individuals have the option to contact the principle student investigator or faculty supervisor. We believe this will be the most ideal method to recruit individuals who meet the required demographics of this project, which will be outlined on the advertisement. I have attached a copy of the advertisement. If you have any further questions please contact:

Carolyn Dyer, Graduate Student  
Department of Kinesiology  
Brock University  
905-246-1966 or [cd06xq@brocku.ca](mailto:cd06xq@brocku.ca)

Dr. Jarold Cosby, Faculty Supervisor  
Department of Kinesiology  
Brock University  
905-688-5550 ext. 5340 or [jcosby@brocku.ca](mailto:jcosby@brocku.ca)

This project was approved by Brock University's Research Ethics Board (12-176). For further questions please contact the Research Ethics Office at 905-688-5550 ext.3035 or [reb@brocku.ca](mailto:reb@brocku.ca).

## Appendix D: Telephone script 1

P = Potential participant; I=Interviewer

I – Hello, may I please speak to [insert name of potential participant]?

P – Hello, may I ask who I am speaking to?

I – Yes, my name is Carolyn Dyer and I am a Masters student within the Faculty of Applied Health Sciences at Brock University. I am currently conducting research under the supervision of Dr. Jarold Cosby on multiple medication use; I received your e-mail regarding your interest in possibly participating in my research project. Would you be interested in learning more about the study?

P – No. (Thank them for their time and say goodbye)

OR

P – Yes.

I – Terrific, as part of my research project I will be conducting one on one interviews with individuals who have been diagnosed with a chronic condition and are prescribed 3 or more medications to treat their condition. The purpose of this project is develop a framework for policy and decision makers within the healthcare industry in understanding the decisions individuals are making in adhering or not adhering to their prescribed medications. Before we proceed any further, I need to ask you a few questions to verify specific demographic factors:

1. Are you male or female? (P answers)
2. Are you between the ages of 40 to 55? (P answers)
3. Have you been diagnosed with a chronic condition? (P answers)
4. Are you currently required to take 3 or more prescribed medications? (P answers) Thank you for answering my questions.

(If P does not fit the inclusion criteria) – Unfortunately this study is looking for certain demographics factors and you do not meet the criteria. I apologize for the inconvenience and would like to thank you for taking the time to speak with me. Goodbye.

OR

(If P does meet the inclusion criteria) – Excellent, I would like to speak to you about your experiences you have had regarding your personal health. Do you have a few more minutes so I can give you some additional information regarding the interview process?

P – No, could you call back later? (Arrange a time that would be best convenient for you to call back).

OR

P – Yes I would be interested in hearing additional information regarding the interview process.

I – Perfect, here is some background information:

- I will be conducting one on one interviews starting this winter.
- The interviews will be conducted at the Health Decisions Lab at Brock University located on 500 Glenridge Ave, St. Catharines, ON.
- The interview will last anywhere from 45 minutes to an hour and an interview time will be selected based upon whenever is most convenient for you.
- Participation in this study is strictly voluntary and you can choose to withdraw from this study at any point in time.
- The interview questions are quite general (i.e. tell me about the medications you are currently taking). Interview questions will be open-ended and allow you to be as detailed as you would like in your response. **I want to inform you that this is not a medical study and there will be no advice given on your medical conditions.**
- You may decline to answer any of the questions you do not wish to answer.
- With your permission, the interview will be audio recorded to allow for transcription and analysis at a later time.
- All information you provided will be considered confidential; I will be using a randomized number system and personal characteristics that would identify who you are will not be used to protect your privacy.
- Two weeks after the study is completed you will be mailed a copy of the results and if you wish to have a copy of your personal transcript, this will be mailed or e-mailed to you within forty-eight hours of when you requested your transcripts.
- The data collected will be kept in a secure location and disposed of one year after the study has been completed.
- With your permission I would like to mail or e-mail you an information package which has all of these details along with contact names and numbers to help you assist in making a decision to participate in this study.

P – No thank you, I am not interested. (Thank them for their time and wish them goodbye).

OR

P – Yes (decide on a method of mailing and obtain contact information from the potential participant, i.e. e-mail or mailing address).

I – Thank you very much!

- If you have any questions or need additional information about this research project, please feel free to contact my supervisor, Dr. Jarold Cosby at 905-688-5550 ext. 5340 or [jcosby@brocku.ca](mailto:jcosby@brocku.ca)

- I would like to assure you that this study has been reviewed and has received ethics clearance through the Office of Research Ethics. Should you have any questions or concerns regarding your participation within this study, please contact the Office of Research Ethics at 905-688-5550 ext. 3035 or [reb@brocku.ca](mailto:reb@brocku.ca)
- I will follow up with you in 3 to 5 days to see if you are interested (or still interested) in being interviewed and we can arrange a time to meet. Thank you for taking the time to talk with me and once again if you have any questions please do not hesitate to contact me at [cd06xq@brocku.ca](mailto:cd06xq@brocku.ca)

P – Goodbye.

I – Goodbye.

## Appendix E: Letter of invitation

April, 2013

**Title of Study:** Multiple medication use in adults: A qualitative study

**Principal Student Investigator:** Carolyn Dyer, Graduate Student, Department of Kinesiology, Brock University

**Faculty Supervisor:** Dr. Jarold Cosby, Associate Professor, Department of Kinesiology, Brock University

I, Carolyn Dyer, Graduate Student, from the Department of Kinesiology, Brock University, invite you to participate in a research project entitled, 'Multiple medication use in adults: A qualitative study'.

The purpose of this research study is to provide health care professionals with a framework in understanding how decisions are made regarding medication adherence for individuals who are taking three or more prescribed medications. **This is not a medical study and at no point in time will medical advice be given.** Should you choose to participate, you will be asked to participate in a one to one interview and share your experiences regarding the decisions you have made regarding medication adherence. The interview will last approximately 45 minutes.

Your participation will provide data that will contribute to an overall increased understanding of the rationale and context behind the decision-making process regarding medication adherence. This will help us in creating a framework for healthcare professionals in understanding the decisions made by patients and how medication adherence can be improved.

This is a single-site project as all interviews will be conducted at Brock University at 500 Glenridge Avenue, St. Catharines, ON. Your involvement in this study is strictly voluntary and you have the right to refuse participation at any time.

If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905-688-5550 ext. 3035 or reb@brocku.ca).

If you have any questions regarding the research study, please feel free to contact Dr. Jarold Cosby or I at any time (see below for contact information).

Thank you,

Carolyn Dyer, Graduate Student  
Department of Kinesiology  
Brock University  
905-246-1966 or [cd06xq@brocku.ca](mailto:cd06xq@brocku.ca)

Dr. Jarold Cosby, Faculty Supervisor  
Department of Kinesiology  
Brock University  
905-688-5550 ext. 5340 or [jcosby@brocku.ca](mailto:jcosby@brocku.ca)



This project was approved by Brock University's Research Ethics Board (12-176). For further questions please contact the Research Ethics Office at 905-688-5550 ext.3035 or [reb@brocku.ca](mailto:reb@brocku.ca).

## Appendix F: Informed consent form

Date: April, 2013

Project Title: Multiple medication use in adults: A qualitative study

Principal Student Investigator:  
Carolyn Dyer, Graduate Student  
Department of Kinesiology  
Brock University  
905-246-1966; [cd06xq@brocku.ca](mailto:cd06xq@brocku.ca)

Faculty Supervisor:  
Dr. Jarold Cosby; Associate Professor  
Department of Kinesiology  
Brock University  
905-688-5550 Ext. 5340; [jcosby@brocku.ca](mailto:jcosby@brocku.ca)

### INVITATION

Brock University's Health Decision Lab would like to invite you to participate in a research study about medication adherence. The purpose of this research is to provide health care professionals with a framework in understanding how decisions are made regarding medication adherence for individuals who are taking three or more prescribed medications.

### WHAT'S INVOLVED

As a participant you will be asked to share your experiences with the researcher. Interviews will be audio digitally recorded and transcribed verbatim. Interviews will take place at Brock University on 500 Glenridge Avenue in St. Catharines, ON. Interviews will be conducted one on one in a conversational manner and will allow you to share your personal experiences of adhering to a prescribed drug regimen specifically how certain organizational and individual factors have affected your decisions (i.e. the cost of medications, individual factors, patient-physician communication, and Canada's healthcare system). **This is not a medical study, therefore, no medical advice will be provided.** Participation will take approximately 45 minutes to an hour of your time in addition to travel time to and from the interview.

### POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include the opportunity to tell your story about your experiences about your personal health, the opportunity to see the interpretation of your experiences, and to understand your experiences in relation to other participants with similar health dilemmas. You will also contribute to an increased understanding of the decision-making process regarding medication adherence. Thus, you are contributing to the development of a framework for healthcare providers in understanding the context and rationale behind medication adherence choices. However, there are some associated risks with participation. Sharing your personal experiences regarding your health may result in increased feelings of emotional distress yet you are given the opportunity to not answer any questions you do not feel comfortable with. Furthermore, the principal student investigator has formal training in qualitative interviewing and is well prepared to manage any such risks.

### CONFIDENTIALITY

The information you provide will be kept strictly confidential. Your name will not appear in any thesis or publications from this study. However, anonymous quotations may be used, which will be done through the use of a randomized number system. Data collected during this study will be stored electronically on a computer hard drive, which is user name and password protected. Data will be kept until the study is completed after which all hard copies of the data will be shredded and electronic copies will be erased. Access to the data will be restricted to the principal student investigator, Carolyn Dyer, and the faculty supervisor, Dr. Jarold Cosby. However, at any time if you wish to access your interview transcript you may do so by contacting either Carolyn Dyer or Dr. Jarold Cosby via telephone or e-mail. All requested transcripts will be delivered within forty-eight hours of the request however once the study is completed

transcripts will not be available since all interview transcripts will be destroyed once the study is completed.

**VOLUNTARY PARTICIPATION**

Participation in this study is strictly voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from the study at any time and may do so without any penalty or loss of benefits to which you are entitled. To withdraw from the study please contact the principal student investigator via telephone or e-mail before the study has been completed and submitted for publication. After the study has been submitted for publication you will no longer be able to withdraw from the study.

**PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available one week after the study has been completed and you may request a copy from either the principal student investigator or the faculty supervisor via telephone or e-mail. All academic papers will be mailed within one week of the request.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the principal student investigator or the faculty supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (12-176). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at 905-688-5550 Ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca). Thank you for assistance in this research project. Please keep a copy of this form for your records.

**CONSENT FORM**

I agree to participate in this study described above; I have made this decision based on the information I have read in the Informed-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name:

Signature:

Date:

## Appendix G: Supporting quotations

Categories	Supporting quotations
Origins of medical condition(s)	<i>I had a hard time too controlling my anger- I first chopped it up to getting married, having a family, her daughter/my daughter, that was a big change for me to so I chopped it up my mood swings to that. But then I was like I don't know they're not that tough to get along with. So that's when I talked to Dr. K. - P11(3)</i>
The impact of others to self-manage condition and medication use	<p><i>My parents don't deal with things head on so there like it's all you, you need to cut down on your eating, and at times I was eating okay like it wasn't always is was eating. And I told them how much sugar I was eating and the diabetes centre for example said that's [...] your pancreas isn't working the way it should. Then I would explain it to my family because my dad diabetic but he was diagnosed at the 13 and I was diagnosed at the 27. So I said to them my parents aren't supportive they were saying it's your diet, you need to change I wasn't always. -P7(6)</i></p> <p><i>He's a great husband. He knew if I was struggling, he knew it. He could tell, he would say you're tired, you're struggling, he'd know that...you need to quit now or could do whatever [...] If I couldn't do it, he would do it. -P10(9)</i></p>
The 'success' and 'failure' associated with self-management	<p><i>So I started learning a bit more about that [depression] and started understanding some of the stuff I was doing, wasn't really good for myself [...] But then I was like I don't know they're not that tough to get along with. So that's when I talked to Dr. K. -P11(3)</i></p> <p><i>[...] so what I do is, don't laugh, I count. So if it happens at night and I'm lying in bed I'll try to count how many days til' Christmas, how many days until somebody's birthday so like a counting strategy kind of thing. -P1(4)</i></p> <p><i>We're lucky, really lucky because Todd's work covers the cost of medication but it doesn't cover therapy [...] if I go see a psychologist it comes out of my pocket [...] that's hard so I really pick and choose when I need it. So if I'm really low then I'll go see them. - P9(6)</i></p>
The ability to maintain privacy	<p><i>[...] this is a rarity for me I don't usually share [...] Ya I don't tell people very much like I said I told my supervisor at work because I get along with him, I told my youngest brother because he knows what it's like. And of course my wife and daughter. -P11(7-8)</i></p> <p><i>I don't trust anyone here [referring to her workplace], not the management, I don't. If my co-workers say you need to go I will say no I will lie through my teeth, I will not tell. I'm part-time so I'm able to hide it so I can take a day and say oh I have an</i></p>

	<i>appointment or whatever but I don't want nobody to know. I will not tell anyone. -P13(9)</i>
The ability to work	<p><i>And now you know I have little nobbles and my hands are starting to turn. So it got to the point, I was a banker and on the computer all the time, it got to the point I couldn't even type. So I have to do voice recognition and you can't do that at the bank. -P9(2-3)</i></p> <p><i>I have some energy, like it was getting to the point where I didn't want to go to work and I normally the one up at 6 the sun shining and I'm out the door walking the dog and now I feel I don't want to do anything. -P8(3)</i></p> <p><i>[...] so my cardiac output at the most severe was 7% of normal so I pretty much flat on my back, I couldn't do anything and I was off work for 10 years. -P14(2)</i></p>
Fear of the future	<p><i>I'm covered 100% but if it wasn't for it I would probably be skipping out on a lot of the drugs because let's face it, they are expensive. -P11(5)</i></p> <p><i>I have a friend he died of cancer and they are the most holistic people, they even made their own frigin dog food. Both of their dogs died of cancer and he died of cancer. So I don't necessarily say 'hey it's in our food', I get some of it is in our food but I'm sure it's the air, in the earth, it's around and I think if you're genetically prone to it there's nothing you can do to stop it. And most people die of old age from cancer anyways. -P10(8)</i></p> <p><i>I know you're going to think I'm crazy now but I know a girl that's bipolar that was taking the same medication and I kept hearing this 'swwwiiishhh, swwwiiishhh, swwwiiishhh, swwwiiishhh' I kept thinking what the frig, is there something wrong with my ears? And she told me that's what happens when you cold turkey it even though I was taking mega, mega stuff. -P10(3)</i></p>
The fear of the dependency on medications	<p><i>But I went off it for a while. And my next door neighbour at the time was a nurse and I didn't really tell her that I've been off it for a few days. And I started to twitch and 2 days later she goes 'what is wrong with you?' 'Oh you know I went off my medications'. I'd be super high and super low kinda thing and she was like 'get back on your medications or otherwise I will never talk to you again'. So apparently it works. -P1(2)</i></p> <p><i>I know if I don't take my panic attack pill I know I have problems because I tried to go off of it on my own which I guess you're not supposed to [...] I was just getting panic attacks and for no reason like just watching TV and say 'Cops' or something was on then the fire was coming from feet right through my body and I was constantly shaking, I</i></p>

	<p><i>couldn't even drive a car. -P6(3,5)</i></p> <p><i>[...] then I think everything is over and settled now with the estate, things have moved on I think I'm going to do better, I'm going to do and I was doing okay but it something that I had a fear of to trigger it. -P10(3)</i></p>
The need for medications	<p><i>Okay, work can get to me, right? Definitely but at the point Katie [participant's daughter] moved out to Alberta, took the kids [...] My parents are moving in well have moved in now. My mother has Alzheimer's, a lot of stress. It's a lot so I'm trying to handle everything there and then seeing her and the kids go, it was bad. So she [referring to her family physician] actually put up my Celexa a little bit and I went down and said you know I'm going crazy kinda thing and she said okay we'll bring it up. -P1(3)</i></p> <p><i>[...] that I don't have the anxiety and depression, that I can sleep because I wasn't sleeping without the medications because I've tried to go off because the sleeping pill is addictive, I'm addicted to it now. So she has to wean me off of it but she hasn't yet because she said sleep is more important but it's been a year, so I'm thinking we need to start cutting the dose back. -P3(10)</i></p>

<p>Emotions associated with being first diagnosed</p>	<p><i>I was very, very, very upset but at the time they said I could look after it with just diet but I did that for a bit then I when I went back it wasn't getting any better so they put me on pills. -P1(1)</i></p> <p><i>So when I did go and see him that's when we find out, Lynda [his wife] went with me and he told me I have type 2 diabetes and high blood pressure. I kind of questioned him because I drink water, I don't drink pop, I don't eat a lot candy and Lynda is the total opposite and I thought did you get the blood samples mixed up because the first is denial. -P4(2)</i></p>
<p>Moving to a new 'normal': dependence vs. the imagery of a warrior</p>	<p><i>[...] from my stepfather passing away it was really hard and that's where it basically started. -P6(3)</i></p> <p><i>My whole life has been about me, where I played, where I coached, the towns I've been in – it's time for me to balance the scales a little bit. And I don't mean to be selfish but everything evolved around me and now it doesn't and I like it. I can give back; balance the scales a little bit. That's the great thing about it and I feel like what I'm supposed to do. I don't want to be remembered as Simon the great hockey player, the great coach, the great TV guy, great writer I rather be remembered as the guy who raised a lot of money for Parkinson's disease. -P12(5)</i></p>
<p>The awareness of being on multiple medications</p>	<p><i>[...] they put me on Prednisone that was the fix all. Of course I just got fat and a big head or whatever you want to call it, it was horrible. I hated it; I will never go on it again unless if I have too, my doctor said I will never go on it again unless I have too. It altered my mind; it made me a totally different person. -P10(1)</i></p> <p><i>I think it was because of the Champix. I mean I was starting to not feel great but I've never had thoughts like that. Even through all those years when I started to get depressed again – I never, never, never did. So I'm pretty sure it was the Champix and they say that is one of the side-effects. -P3(3)</i></p>