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# The Relative Influences of Knowledge, Beliefs and Preferences on Adherence to Asthma Medication

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A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy

# THE RELATIVE INFLUENCES OF KNOWLEDGE, BELIEFS AND PATIENT PREFERENCES ON ADHERENCE TO ASTHMA PREVENTER MEDICATION

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by

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The thesis by

**Naomi J. Gryfe Saperia**

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## Abstract

**Purpose:** Patients' decisions about whether or not to adhere to their prescribed regimens are shaped not only by their knowledge and beliefs about their condition and its treatment options, but also by what they value in these domains. This study represents an integration of theory and methods from nursing/public health, psychology and economics to explore the additive effects of knowledge, beliefs and preferences on adherence to preventer medication in a sample of patients with asthma. It was hypothesized that knowledge, beliefs and preferences pertaining to long term outcomes would independently predict improved adherence. **Method:** 140 patients with asthma were asked to complete a series of surveys assessing their knowledge and beliefs about asthma and its treatments as well as a discrete-choice task (DCE) in which they selected which hypothetical medication they would choose from among eight choice sets that varied along seven attributes (Long Term Efficacy, Short Term Efficacy, Immediate Relief, Number of Inhalers, Steroid Dose, Administration Time, and Side Effects). Adherence was measured using the self-report Medication Adherence Report Scale one month after their clinic visit. **Results:** A latent cluster analysis of the DCE data suggested four distinct groups of patients, namely, those whose choices were guided by (1) long term benefits, (2) medication side effects, (3) the trade-off between side effects and efficacy and (4) all attributes equally. Multiple regression analyses indicated that pathophysiology knowledge, the belief that preventer medication is necessary and membership in the group valuing long term outcomes each uniquely predicted reported adherence, together explaining 39% of the variance. Preferences for long term outcomes predicted an additional 10% of the variance above and beyond that accounted for knowledge about

asthma pathophysiology and treatment beliefs alone. **Conclusion:** These findings suggest that to improve patient adherence to asthma preventer medications, patients should be helped to understand *why* they require medications. Once the long term effects of asthma are understood, believed *and* valued, patients will be more likely to adhere. Via DCE methodology, we have also demonstrated a novel approach to elucidating patient variations in treatment-related values.

*Key Words:* Asthma, Adherence, Illness Beliefs, Treatment Beliefs, Knowledge, Discrete Choice Experiments

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## Introduction

Decision making is a fundamental part of the health care provision process. From patients' initial decision to seek treatment, to the treatment option(s) offered by the health care provider, to whether patients choose to adhere to the regimen – all are decisions that affect the course of an illness. There is increasing recognition of the importance of including patients in the health care decision making process (Little et al., 2001). Systematic reviews have shown that involving patients in treatment planning results in better quality of care, higher patient satisfaction and self-esteem (Crawford et al., 2002; Kinnersley et al., 2007), improved physical outcomes (Michie, Miles, & Weinman, 2003) and better self-management by patients (Heisler, Bourknight, Hayward, Smith, & Kerr, 2002; Mead & Bower, 2002). Thus, collaborative decision making is increasingly being recognized as the key to effective control of chronic diseases (Leventhal, Weinman, Leventhal, & Phillips, 2008).

According to the World Health Organization (2003), in the developed world, roughly half of those with chronic diseases fail to use their medications- often a central component of self-management plans- as recommended. Suboptimal patient adherence to chronic disease management programs poses a serious health threat. Therefore, although governments and health organizations invest considerable effort and expense developing and improving efficacious treatments, these resources are wasted if the programs are not reliably adopted by patients.

In an effort to combat non-adherence, practitioners and researchers, largely drawn from the fields of public health, medicine and nursing have developed and implemented educational programs aimed at enhancing patients' *knowledge* about their conditions and

associated treatments. In contrast, the psychological literature has tended to focus on patients' *beliefs* about their conditions and treatment options. However, as the ensuing literature review will indicate, targeting what people know and believe is not sufficient to influence adherence.

Health care decision making is a complex process which involves the weighing of risks and benefits as well as personal values (Schapira, Gilligan, McAuliffe, & Nattinger, 2004). The central tenet of this thesis is that to understand and subsequently improve adherence, one also has to know what *matters* to people, that is, their values and preferences. Values and preferences, while not a focus in the adherence literature, have been of interest to health economists invested in gauging health care consumer's "willingness to pay" for services and treatments. To do so, they have developed a range of innovative approaches to assess patient preferences, one of which- the Discrete Choice Experiment- will be used in this study.

To date, research on patient knowledge, beliefs, and preferences has been conducted largely in different professional 'silos' (nursing/policy, psychology and economics, respectively).Yet, knowledge, beliefs and preferences likely work additively on adherence and should be examined in tandem. For example, patients may *know* that an inhaled corticosteroid is designed to prevent subsequent asthma attacks, but this does not necessarily mean that they *believe* it will help control their asthma symptoms. Similarly, patients may *know* that a preventer medication is designed to improve their asthma in the long-term (but not relieve their symptoms in the short-term) and *believe* that it will work. However, they may be seeking treatment for immediate symptom relief and are, therefore, disinclined to use a medication that will prevent long-term effects. In essence,

although correct knowledge and treatment-compatible beliefs may steer patients towards making the proper health care decisions, without the necessary motivation, patients will not engage in the behaviour. As noted by the World Health Organization (WHO, 2003, p. 44), "Patients' *knowledg*e [italics added] and *beliefs* [italics added] about their illness, *motivation* [italics added] to manage it, confidence in their ability to engage in illness management behaviours and expectations… interact in ways not yet fully understood to influence behaviours".

Accordingly, this research project represents an integration of theory and/or methods from three disciplinary literatures- nursing/public health, psychology and economics- to explore the additive effects of knowledge, beliefs, and preferences on preventer medication adherence in a sample of patients with asthma. In the sections that follow, the relevant literatures in these three spheres are reviewed with an eye towards showing how current efforts to increase adherence in the domain of asthma self-management have been hindered by not taking into account all three elements.

# Chapter I: Literature Review

## Adherence: An Ongoing Challenge

Given that the benefit of medical advice is contingent on whether or not patients choose to follow it, adherence has been deemed the "key" mediator between medical practice and patient outcomes (Kravitz & Melnikow, 2004). The consequences of non-adherence are troubling. They include poor medical outcomes, higher health care costs, as well as increased frequency of emergency room visits (Phillips, 2008). In general, adherence rates tend to be lower for chronic than acute conditions (WHO, 2003). Anywhere from 20-50 percent of patients with chronic conditions do not adhere to their prescribed medication regimen (Kripalani, Yao, & Haynes, 2007) and more than 70 percent do not adhere to their diet or exercise programs (Their et al., 2008). Pulmonary diseases, diabetes and sleep disorders are chronic conditions with the lowest adherence rates (DiMatteo, 2004).

Accordingly, although there has been widespread improvements in our understanding of the pathophysiology of many conditions and consequently treatment efficacy (Sweeny, Edwards, Stead, & Halpin, 2001), treatment effectiveness has not kept pace with these developments. Thier et al. (2008) conducted a retrospective analysis of claims from a national insurer and found that, although physicians, on average, tended to follow evidence-based practice guidelines 59 percent of the time, patients followed their physician's advice only between 11 and 42 percent of the time.

Research on the gap between physician's recommendations and their patients' behaviours has shown that treatment characteristics, such as medication side effects (Catz, Kelly, Bogart, Genosch, & McAuliffe, 2000) and treatment complexity (Ley,

1997) negatively correlate with adherence. In contrast, contextual factors such as social support (Tanner & Feldman, 1997) and the quality of the patient-physician relationship (Ciechanowski, Katon, Russo, & Walker, 2001) positively correlate with adherence. Other predictive factors include, but are not limited to, poor instruction by the health care provider, poor patient memory and cost of treatments (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008).

**Adherence Interventions: Is Education Enough?**

Poor adherence rates have catalyzed practitioners and researchers to develop interventions to improve adherence in a broad range of populations and across a large number of treatments. Educational interventions to improve adherence have been applied to a range of patient populations, including individuals with asthma (e.g., Lemiere et al., 2003), chronic heart failure (Clark et al., 2009), hypertension (Devine & Reifschneider, 1995; Schroeder, Fahey, & Ebrahim, 2004), hyperlipidemia (Schedlbauer, Schroeder, Peters & Fahey, 2004), diabetes (Lutoto et al., 2011), HIV (Khachani, et al., 2011) and chronic obstructive pulmonary disease (Simone et al., 2011). Unfortunately, although some successful interventions exist, at least half fail to produce meaningful changes in adherence (van Dumlen et al., 2007). Moreover, many interventions are time consuming and complicated and result in only modest behaviour changes (Awad, 2004; Simpson, 2006).

After conducting a systematic review of 38 reviews of the literature on adherence in the health care domain across a wide range of conditions, Van Dumlen et al. (2007) concluded that technical (e.g., reducing the complexity of treatment) and behavioural interventions (e.g., memory aids, reminder calls, etc.) were most effective. However,

education, defined as "any intervention given with the intent of improving the person's ability to manage his or her disease" (p. 9), though effective in the short term, was less effective over time. For example, an educational program for those with diabetes yielded strong immediate (post-intervention) effects ($d$ = 1.05) on adherence, but smaller effects at four week follow-up ($d$ = .46; Devine & Reifschneider, 1995).

Haynes et al. (2008) conducted a review of the efficacy of a broad range of adherence interventions that involved instruction and counseling about a disease in conjunction with other approaches (e.g., family and/or couple intervention, psychotherapy, group meetings, providing reminder aids, or a combination thereof). They found that less than half (45%) yielded statistically significant improvements in adherence. Moreover, those that were most effective in the long term were quite labour intensive, thereby reducing their cost-effectiveness and clinical utility.

Van Dumlen et al. (2007), commenting on the stagnancy of adherence rates over the prior decade despite research proliferation, suggest it might be due to the lack of guidance by suitable theoretical frameworks. Moreover, most interventions do not take patients' perspectives into account. Rather, they give patients information and erroneously assume that they will then "think the right way" and behave accordingly. However, helping physicians recognize that their patients' views of their condition may not match their own has been shown to improve physical and mental functioning (Berkanovic, Hurwicz & Lachenbruch, 1995) and to decrease poor medical appointment attendance (Chesney, Brown, Poe, & Gary, 1983). Therefore, for adherence intervention research to move forward, we need to better understand how patients' health beliefs and

perspectives lead them to follow (or not) health care recommendations. This literature is reviewed in the upcoming section.

**Psychological Theories of Health: Do Beliefs Have a Role to Play In Medical Decisions?**

Health psychologists have long been interested in how individuals perceive their health and what guides health behaviours. Early models, such as the Health Belief Model (Janz & Becker, 1984), the Theory of Reasoned Action (Ajzen & Fishbein, 1980) and the Subjective Expected Utility Theory (Sutton, 1982) emphasize the role of perceived health risks in predicting health protective behaviours. However, these models rely on the assumption that people use information in a linear fashion when deciding how to behave (Brannon & Feist, 2004). The more recently proposed Transtheoretical Model (Prochaska & DiClemente, 1983; Prochaska, Redding, & Evers, 2002) better accounts for the complexity of health care decisions, in that it suggests that people move through a sequence of defined, qualitatively different stages (i.e., precontemplation, contemplation, preparation, action, maintenance) and takes into consideration how people initially consider a problem as well as how they decide to act and maintain health actions. However, this model has not been adequately supported by the literature as there is little evidence for sequential movement across stages (Little & Girvin, 2002). Furthermore, the model has not proved to be particularly predictive in longitudinal studies (Wilson & Schlam, 2004).

To date, perhaps the most comprehensive model of patient health-protective behaviour is Leventhal and colleagues' (1984) Common Sense Model of Illness (CSM). The CSM is predicated on a recursive, parallel processing system which is proposed to

explain both the development and maintenance of health behaviours (Leventhal, Nerenz, & Steele, 1984; Stuifbergen, Phillips, Voelmeck, & Browder, 2006). According to the CSM, the noticing of symptoms or the receipt of a diagnosis activates schematic and organizational frameworks, referred to as cognitive and emotional illness representations. Cognitive and emotional representations work in parallel, but are proposed to have reciprocal influences (Wearden & Peters, 2008). They prompt coping behaviours, the consequences of which are appraised by the individual for effectiveness and changed based on the information gleaned during the appraisal phase (Hagger & Orbell, 2003; Leventhal, Brissette, & Leventhal, 2003; Scharloo & Kaptein, 1997).

Research over the past few decades (Hagger & Orbell, 2003; Moss-Morris et al., 2002; Rutter & Rutter, 2007) has shown that cognitive representations can be grouped into five distinct but correlated domains including: (1) individual beliefs about the diagnostic label and associated symptoms (identity), (2) beliefs about the cause, (3) beliefs about the course of the illness (timeline), (4) views about the consequences of the illness and (5) beliefs about the controllability of the disease. More recently, illness coherence, or the extent to which individuals feel they understand their illness, has been added as a domain (Moss-Morris et al., 2002).

The construct and discriminant validity of these five cognitive components have been studied extensively (Hagger & Orbell, 2003; Heijmans & de Ridder, 1998; Frostholm et al., 2007; Moss-Morris et al., 2002; Petrie, Jugo, & Devcich, 2007; Rutter & Rutter, 2007). Evidence for the distinctness of the categories has been found in studies of patients with chronic illnesses (Leventhal et al., 1984), acute illnesses (Lau, Bernard, & Hartman, 1989) as well as among undergraduates assessing hypothetical illness (Bishop,

Briede, Cavazos, Grotzinger, & McMahon, 1987). A meta-analysis of 45 empirical studies suggests strong support for a consistent five factor structure and provides evidence of conceptual distinctions among the domains (Hagger & Orbell, 2003). Moreover, to-be-expected relationships among the domains are observed, with high positive correlations between the identity, chronicity and consequences domains and strong negative correlations among the identity and cure dimensions. That is, patients who attribute more symptoms to their condition construe it as having a larger impact on their daily functioning and see it as more chronic.

Empirical studies have supported the hypothesis that illness representations are associated with health outcomes. For example, illness representations have been shown to predict return to work (Lacroix, Martin, Avendano, & Goldstein, 1991), success in coping with chronic illness (Hampson, Galsgow, & Toobert, 1990) and functional outcomes (Petrie, Jago, & Devcich, 2007; Scharloo et al., 1998). A considerable amount of literature also exists on the illness representations of patients with cardiac disease (Cooper, Lloyd, Weinman, & Jackson, 1999; Lau-Walker, 2006), type II diabetes (Hampson et al., 1990), psoriasis (Fortune, Richards, Main, & Griffiths, 2000), kidney disease (Fowler & Baas, 2006), cancer (Hagger & Orbell, 2006; Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doorn-op den Akker, & Kaptein, 2005), rheumatoid arthritis (Murphy, Dickens, Creed, & Bernstein, 1999; Scharloo et al., 1998), Addison's disease (Heijmans & de Ridder, 1998) and epilepsy (Kemp, Morley, & Anderson, 1999). The importance of each dimension varies among the conditions. In the context of various illnesses, cognitive illness representations have been shown to be related to the decision to seek health care (Leventhal, Diefenbach, & Leventhal, 1992)

and satisfaction with medical consultations (Frostholm et al., 2005). Additionally illness representations have been associated with quality of life at a six month follow-up (French, Lewin, Watson, & Thompson, 2005).

Thus, there is good evidence that patients' subjective interpretations of their physical ailments, or the "psychology" of physical symptoms has implications for health outcomes. Moreover, certain dimensions of the illness model are differentially associated with outcomes. For example, the perception of a strong illness identity, serious consequences and chronic timeline are negatively associated with psychological and physical well-being, whereas those with greater perceived control of their illness do better psychologically and socially (Hagger & Orbell, 2003). It should be noted that the majority of studies in this arena are cross-sectional, which makes it difficult to discern whether these illness representations caused maladjustment or were its consequence.

**Beliefs and Adherence**

Leventhal et al. (2003) postulate that the process of constructing a representation is symmetrical in that there is pressure to connect both abstract (disease labels and the meaning of illness) with concrete physical symptoms. That is, once patients are given a diagnosis, this hierarchical processing system compels them to search for symptoms that confirm the diagnosis. Similarly, experiencing symptoms motivates individuals to seek out a diagnosis. The interpretation of both sources of information leads to the formation of distinct thematic dimensions that comprise a cognitive illness representation and have important implications for treatment adherence. For example, in an actively treated sample of patients with hypertension, Meyer (1981, as cited in Leventhal, Nerenez & Steele, 1984) noted that the majority of the group used vacillations in a symptom to

monitor changes in their condition. Of the patients who believed that the treatment was acutely and directly affecting their symptoms, 70% were compliant with their medication. In contrast, only 31% of patients who felt the medications were not affecting their symptoms adhered to the treatment regimen, suggesting that perceived symptom reduction is an essential component of medication adherence. These findings demonstrate the difficulty in promoting adherence to occult conditions that do not provide feedback in the form of symptom relief.

Horne and Weinman (2002) have argued that the CSM be extended to include beliefs about the necessity of a treatment and concern for the adverse effects of medications, because just as people have thoughts and beliefs about their illnesses, they have thoughts and beliefs about the treatments being offered (Horne, 1996). In a study of patients with several chronic disorders (i.e., asthma, diabetes, cardiac disease, and cancer), Horne and Weinman (1999) found that self- reported non-adherence was correlated with doubts about the necessity of the medication and concerns about potential adverse effects. Thus, treatment beliefs are now frequently assessed alongside illness beliefs, particularly when adherence is the outcome of interest. Beliefs, both about illnesses and their treatments, have been shown to predict adherence to, among others, HIV HAART treatment (Gellaitry et al., 2005), coronary treatments (Sud et al., 2005), asthma preventer medication adherence (Horne & Weinman, 2002), Type II diabetes treatments (Farmer, Kinmonth, & Sutton, 2006) and follow-up attendance at a lipid clinic (Avishay, Lishner, & Melamed, 2011). Moreover, a narrative systematic review of both patient and pharmacy level studies identified patients' concerns for their treatment as well

as their perception that medication was not necessary as the primary reasons they did not fill their prescriptions (McHorney & Gadkari, 2010).

While beliefs account for a considerable amount of variance in adherence (approximately a quarter of the variance as per Horne and Weinman, 2002), they do not tell the whole story. As Kuhl (2000) notes, cognitive representations and subsequent coping strategies cannot energize behaviour unless they have personal meaning. In other words, behavior may be influenced by factors beyond clinical efficacy, including how patients weigh the costs (e.g., side effects, inconvenience, and price) and benefits (e.g., immediate and long term symptom relief) of treatments, as well as how i*mportant* these costs and benefits are to them. As has been argued (Chapman & Sonnenberg, 2000) patients choose whether or not to adhere, and so a better understanding of what drives the decision would be helpful.

**Decision Theory: What Really Matters to Patients?**

Decisions, ubiquitous to daily life, are important in so far as they direct behaviours. Ultimately, it is values and preferences that drive decisions and choices (an overt expression of what is important to people) and their associated behaviours. In addition, the value one places on the outcome motivates behaviours (Borders, Earleywine, & Huey, 2004). To make a decision, one has to consider the range of available options, each of which vary along a range of attributes. Each attribute, in turn, is differentially valued. Thus, decision making can be a cognitively demanding task, made even more difficult when stakes are high, as is the case with one's health.

Notably, decisions are easy when one outcome is clearly valued over another. For example, some individuals may value being medication free. But, these same individuals

may place more value on their eyesight than being medication free. Consequently, when faced with the decision as to whether to take their medication for glaucoma or risk becoming blind, they opt for the medication. Decisions become considerably more complicated when valued outcomes are equally preferred. In fact, often it is not until values come into conflict that individuals realize that they have competing values (Schwartz, 1996). For example, patients with asthma may not want to take a medication containing steroids but also want to improve their symptoms in the long term. When this occurs, people are required to make "trade-offs" between different attributes to ultimately make their choice and act upon it.

Cognitively engaging in the trade-off process can be difficult and stressful (Tetlock, Peterson, & Lerner, 1996). First, individuals may be hesitant to make these types of decisions because the more important the value, the greater the potential for anticipatory regret over the sacrificed value (e.g., getting rid of a pet because one is allergic to it and the allergies exacerbate one's asthma). Second, these types of decisions involve difficult cognitive comparisons, as it is often the case that options are not evaluated along the same metric. For example, how does one weigh the love of pet against one's long term health?

The Value Pluralism Model (VPM; Tetlock 1986) was proposed to explain the cognitive strategies people use when it is necessary to make the kinds of trade-offs described above. The theory suggests that individuals use increasingly complicated coping strategies as trade-offs become increasingly difficult. If the value conflict is weak (i.e., if one value is clearly stronger than another) individuals will downplay the weaker value and focus on the stronger value (termed denial and bolstering). As the value

conflict increases, individuals begin to engage in lexicographic strategies in which they use the most important value as a criterion to rank order their options and select the highest ones. The most intense conflicts involve the comparison of interdimensional values and at this stage individuals will use explicit trade-off reasoning, deciding how much of one value they are willing to give up for the other (Tetlock, Peterson, & Lerner, 1996).

Trade-offs are inherent in decisions about whether or not to adhere to a prescribed treatment regimen. As Horne et al. (2007) note, "In real life, patients make choices between different attributes of the disease and its treatment, trading off one aspect for another (p. 11)". Given that real life decisions involve trade-offs, health economists have developed techniques to quantify patients' decisional "trade-offs" (Lanscar et al., 2007; Lanscar & Louviere, 2008). Economic models, however, assume that preferences are stable, consistent and rational (Phillips and Abramson, 1992). Because of the assumption that preferences remain stable, health economists have been less concerned with how preferences emerge. Moreover, classic economic theory has had difficulty explaining inconsistent choices (Phillips, Johnson, & Maddala, 2002), though it should be noted that the sub-field of behavioural economics, spawned by Kahneman and Tversky's (1979) Nobel winning work on cognitive heuristics, has made some significant inroads in this domain.

**Measuring preferences.**

Measuring patient preferences for health care interventions and medications, however, has proven to be a significant challenge for health care researchers (Phillips et al., 2002). Many rely on attitude surveys in which individuals are asked to indicate the

extent to which they favour or disfavour a particular entity (Eagly & Chaiken, 1996). However, attitudes (i.e., judgments about the degree of like or dislike for something) are not the same as preferences. Preferences, by definition, involve the relative weighing of one option against another. For example, one may have a strong negative view/attitude of medication side effects. However, when given the choice between taking a medication with known side effects and taking no medication, people might choose medication because alleviating symptoms is more highly preferred than experiencing side effects.

The theoretical differences between attitudes and preferences have methodological implications. The social psychology literature on attitude measurement is vast and the most widely used instruments tend to involve ranking or rating scales. However, ranking or rating scales do not allow for the assessment of trade-offs so relevant to daily life. Methodologies used in the field of economics more accurately assesses preferences and trade-offs. In particular, recent studies have employed a type of conjoint analysis, known as discrete choice experiments (DCEs).

In DCE's, individuals' preferences are revealed through their pattern of choices when presented with multiple pairs of hypothetical scenarios. The technique assumes that a product or program (or for the current purposes, treatment) can be described by a range of characteristics or attributes (Lanscar et al., 2007). Each scenario contains a series of these attributes, varying along different levels. The combinations of the levels of each attribute vary across the scenarios such that when respondents make decisions about the gestalt of the scenarios, they are, in essence, making "trade-offs" between the attributes. By analyzing their pattern of choices, it is possible to glean the extent to which people value each attribute (McTaggart-Cowan et al., 2008).

The application of DCE methodology to discern patient/health care consumer preferences is relatively new. However, research suggests that it provides different information than attitude surveys. For example, Phillips et al. (2002) compared the preferences gleaned from an attitude survey and a conjoint analysis tasks. Their participants observed that they had to think 'harder' while doing the conjoint analysis task than attitude survey. And, while the approaches yielded some consistent results, there were halo effects in the attitude survey wherein respondents used evaluations of one attribute as a marker for other attributes. Consequently, an attribute that was ranked highly on the rating task turned out to be the least significant predictor of choice when participants were forced to make trade-offs in the conjoint analysis task.

Given that DCEs allow for the consideration of the mix of outcome (e.g., improved health in 10 years) and process (e.g., treatment regimen characteristics) variables, DCEs serve as an ecologically valid measure of patient preferences and are useful to address policy relevant issues and patient preferences for medical treatments (Kellet, West, and Finlay, 2006). DCEs have also demonstrated good levels of both internal and convergent validity and have been shown to be relatively insensitive to the ordering and levels of attributes (Ryan, Bate, Eastmond, & Ludbrook, 2001). As such, DCE's may help us better to understand the role that complex tradeoffs play in patients' decision making about medical treatments, such as the one required for asthma. For example, an individual with asthma may believe (correctly) that using a corticosteroid inhaler on a daily basis will prevent subsequent attacks, and also believe (correctly) that corticosteroid use is associated with a slight risk of long term effects, such as bone loss. However, the extent to which this patient uses his/her steroid inhaler on a daily basis (as

prescribed) may be driven in part by the relative 'weight' he/she places on these two factors, as well as on other treatment features (e.g., number of inhalers, immediate versus delayed symptom relief, frequency of dosing, etc.).

Notably, DCE research tends to be descriptive rather than predictive in nature. That is, studies employing this technique have sought to describe group characteristics of patients. This has limited the use of this methodology in psychology, which primarily is concerned with processes and with predicting behaviour at the level of the individual rather than group. Data at the group level and individual level both have their limitations. Whereas aggregate data may over-generalize preferences, individual data may paint a mosaic of preference that cannot easily be used by policy makers to help guide the development of cost effective interventions. There is, therefore, a potential benefit of an intermediate approach, whereby one captures the heterogeneity of preferences within a large group by identifying subgroups with specific preference profiles. To date, only a couple of studies have extracted subgroup data from a conjoint analysis. Namely, Singh, Cuttler, Shin, Silvers and Neuhauser (1998) found five preference patterns among patients considering growth hormone therapy and Cunningham et al. (2008) identified subgroups of parents based on their preferences for children's mental health care. However, both studies are descriptive in nature in that the predictive value of these preference patterns was not examined.

This study will apply this methodology within a predictive model, by examining the extent to which subgroup differences in preferences about various asthma-related states and treatment characteristics predict adherence to preventer medication.

**Asthma: A Case in Point for Studying Knowledge, Beliefs and Preferences**

Asthma is a serious illness, resulting from both chronic inflammation and intermittent constriction of the airways (Holgate, Price, & Valovirta, 2006), the latter producing the rapid onset of respiratory symptoms (i.e., asthma attack) such as breathlessness, coughing and wheezing. In contrast, while inflammation does not directly cause acute symptoms, it does so indirectly by increasing the frequency of bronchoconstrictive episodes. Thus, given the phasic (bronchoconstrictive) and tonic (inflammatory) nature of its underlying pathophysiological processes, asthma treatment guidelines stipulate the overall goals of asthma control should include both day to day symptom control as well as minimizing future risk (O'Bryne, 2010).

Accordingly, optimal management of asthma involves the use of both corticosteroids as a preventive medication to decrease the chronic inflammation, as well as the use of rescue/reliever medications to alleviate the constriction of the airways and associated symptoms of an acute attack (Ohm & Aaronson, 2006). Rescue medications, which reduce broncoconstriction, produce an immediate improvement in symptoms. As such, they are inherently negatively reinforcing, which likely means patients do not need convincing or reminding to use their rescue inhalers. In contrast, preventer medications, typically prescribed for daily use, target the underlying pathophysiology (airway inflammation) and do not provide immediate symptom relief (i.e., are not negatively reinforcing). Recently, a new class of "combination inhalers", which combine preventer and rescue medications in one inhaled dose, was introduced. This regimen requires patients to take a prescribed dose regularly for the subsequent rescue puffs to be effective (C. Licskai, personal communication, October 2008).

The incidence of asthma has increased substantially over the past 20 years and the increased health care costs, missed days of work and lost productivity pose a heavy economic burden (WHO, 2003). Non-adherence to preventer medications is widespread, and adherence to asthma medications is the poorest of that for all other chronic medical conditions (Claxton, Cramer, & Pierce, 2001; DiMatteo, 2004). Despite physicians' best efforts to prescribe according to empirically supported treatment guidelines (in fact, the highest for any disorder), patient non-adherence rates to preventer medications were 37 percent and 42 percent for adults and children, respectively (Bender, Milgrom, & Rand, 1997; Thier et al., 2008). In other words, there is a large gap between the efficacy of treatments and their use in controlling the disorder (Hancox et al., 2010).

As such, most individuals with asthma experience an inadequate level of control, which leads to unnecessarily high morbidity, mortality, and health care burden (Anis et al., 2001; Horne, 2006). These increases are unwarranted because asthma is a disease that *can* be effectively controlled through self-management.

**Factors Affecting Asthma Adherence**

According to the World Health Organization (2003), non-adherence to inhaled corticosteroids results from a number of factors, broadly classified into five categories: (1) Socioeconomic factors (poverty, family dysfunction, fear of health system, cultural and lay beliefs about illness), (2) Health care factors (health care providers' inadequate knowledge and lack of training in behaviour change principles), (3) Condition- related factors (inadequate understanding of the disease), (4) Therapy related factors (complexity of treatment, duration of therapy, adverse effects of treatment), and (5) Patient related factors (forgetfulness, misunderstanding, drug abuse). In addition, patient personality

factors, such as having a high external locus of control, being highly extroverted, as well as scoring low on social desirability measures, have been demonstrated to be associated with poor adherence to asthma medications and monitoring (Halimi et al., 2010).

The WHO goes on to suggest that guidelines for the management of asthma should consider these factors and argues that the majority of factors (2 -5) can be remedied by asthma education programs. Consequently, policy makers and government officials have tried to narrow the efficacy-effectiveness gap for asthma treatments by advocating and implementing educational programs to enhance patients' knowledge about asthma and its treatment (Allen & Jones, 1998; Schaffer & Yarandi, 2007).

**Current Asthma Adherence Intervention Programs**

While recent reviews have suggested that interventions need to be multifaceted and incorporate behavioural and educational components (Haynes et al., 2008; Roter et al., 1998; van Dulmen et al., 2008), the majority of asthma adherence interventions are solely focused on education. At the recommendation of the National Asthma Education Prevention Program (Bethesda, 1997), standard content areas in asthma education programs include basic information about (1) the pathophysiology of the disease, (2) the different roles of preventer versus relief medications, (3) the proper techniques for using inhalers, (4) self-monitoring approaches, and (5) ways to reduce environmental triggers (Janson, Hardie, Fahy, & Boushey, 2001). However, evidence for the effectiveness of knowledge-focused interventions is mixed, at best. As has previously been argued, this is likely due to the fact that, to date, these interventions have addressed neither beliefs nor preferences. In examining these interventions, it is essential to differentiate those that involve purely educational interventions (knowledge interventions) and those that target

self-management (i.e., behaviours), as they can be expected to produce different outcomes (Leventhal & Cameron, 1987).

**Knowledge interventions.**

Evidence for the effectiveness of knowledge- based interventions on preventer medication adherence is mixed. In a meta-analysis of the effectiveness of asthma education programs, Bender, Milgrom and Apter (2003) cited nine studies demonstrating significant enhancement of asthma control. Yet, Ho and colleagues (2003) found no relationship between knowledge and adherence to an asthma treatment regimen. Moreover, Bailey et al. (1999) found that patients receiving educational materials and one hour of individualized education sessions were no different from a standard care group in terms of functional status at follow-up. A similar null finding recently was observed in a sample of adults above the age of 65 (Baptist, Talreja, Clark, 2011). Furthermore, several studies have shown improvements in knowledge following an educational intervention yet no changes in asthma control or adherence (Cote et al., 1997; Garrett et al., 1994; Lopez-Vina & Castillo-Arevalo 2000).

Notably, the shortcomings associated with knowledge measures may obfuscate the ability to interpret the effect of knowledge based interventions. For example, Allen and Jones (1998) developed a general knowledge of asthma questionnaire, which served as the primary outcome measure in an effectiveness trial of an asthma education program. The survey, however, did not differentially assess knowledge about preventer versus rescue medications nor did it assess knowledge about how these two classes of medications target the pathophysiology of asthma. A more recently developed asthma questionnaire (Schaffer & Yarandi, 2007) rectified some of the problems associated with

earlier surveys, but continues to have a number of limitations including the failure to address knowledge about asthma pathophysiology as well as the absence of items about combination inhalers, which have properties of both preventer and rescue medications.

The failure to assess patients' knowledge of asthma pathophysiology is problematic, in that it's crucial to understanding why preventer medications are needed. Taylor and Bower (2004), for example, demonstrated that giving people an explanation as to *why* they should follow instructions enhances compliance. Thus, an intellectual understanding of the "why" may be particularly important for adherence to medications that, like asthma preventer medications, do not immediately yield symptom improvement.

**Self-management interventions.**

According to the World Health Organization (2003), self-management programs have been shown to be cost-effective, reducing both direct (hospitalizations) and indirect (loss of productivity) costs. However, individual studies seem to suggest otherwise. For example, Bailey et al. (1999) randomly assigned 236 asthmatic patients to receive either (1) usual care, (2) an asthma self-management skill-oriented program consisting of a minimum of two group sessions in which they focused on a workbook about asthma triggers and care services as well as how to use a peak flow meter in addition to follow-up reminder phone calls at one, two and four weeks, or (3) a shorter version of the workbook and a 15 minute session with a nurse educator. Despite the investment of time, neither intervention group improved more than the standard care group.

Similar null findings were observed by Morice and Wrench (2001) who randomized 80 patients with acute asthma admitted to hospital into two groups: (1)

control group who received standard care, and (2) an intervention group who received a minimum of two one-on-one 30 minute sessions with a nurse educator with the goal of developing an individualized self-management plan. Hospital re-admission rate, their primary outcome variable, was the same for both groups four months post-discharge. However, as the authors acknowledge, the study may have been insufficiently powered to adequately assess group differences. Levy et al. (2000) delivered a similarly complex and controlled nurse educator delivered intervention. The intervention improved self-reported adherence as well as symptoms at six month follow-up amongst the severe asthmatic patients in their sample, but not in those with mild asthma.

**Conclusion: Knowledge is not enough.**

Despite these mixed findings, experts rightly note that correct knowledge is a prerequisite for self-management (Gibson & Boulett, 2001; Gibson, Ram, & Powell, 2003). However, studies that have demonstrated that educational interventions focusing on these content areas improve asthma control (e.g. Bonne et al., 2002; Couturaud et al., 2002) all have entailed time consuming educational programs that take place over a series of weeks or even months. Indeed, coverage of all content areas dictated by educational guidelines would require a significant amount of clinician and patient time, making the cost-effectiveness and even patient attendance of the educational program themselves potential concerns.

What has become clear is that educational interventions alone are not sufficient. Accordingly, recent adherence intervention programs have begun to incorporate client-specific risk factors to improve adherence (Jinhee et al., 2010). Moreover, Elliot (2006) suggests that knowledge based interventions, while providing patients with correct

factual information fail to address patients' misguided beliefs about asthma, thereby limiting their effectiveness. The psychological literature on lay illness beliefs and models helps one to understand why, despite increased knowledge following education programs, a patient's behaviour may remain unchanged.

**Beliefs about Asthma**

The proper use of asthma medications requires patients to understand both the chronic (tonic) nature of the disease as well as the episodic (phasic) exacerbation of the symptoms associated with the disorder. Most patients, however, view asthma as a series of discrete acute illnesses, separated by what appear to be (given that they are asymptomatic) normal, disease-free time frames (Insel, Meek & Leventhal, 2005). Halm, Mora, and Leventhal (2006) found that 53% of asthmatic patients believed that their asthma was episodic because they had symptoms only occasionally. In essence, patients subscribed to the view that when they have no symptoms, they do not have asthma. This poses a significant problem for medication adherence, as patients with asthma who hold this belief adhere less to their preventative treatment regimens (Halm et al., 2006; Horne & Weinman, 2002). As a case in point, Jessop and Rutter (2003) explored the role of illness beliefs on asthma medication adherence and found that those who believed their asthma could be controlled were more likely to adhere to their preventer medications, whereas those who attributed their asthma symptoms to external causes (e.g., environmental pathogens) were less likely to adhere.

Asthma specific *treatment* beliefs that drive adherence to corticosteroid inhalers may be particularly instructive. As noted earlier, corticosteroids, prescribed as 'preventer' medications for asthma, offer no immediate symptom relief. Rather, they

afford only long-term benefits (Hand & Bradley, 1996), decreasing the number of future asthma attacks by improving lung functioning and presumably preventing structural airway changes (Bender et al., 1997). Also as noted earlier, given that preventer medications are not negatively reinforcing (i.e., they do not immediately remove symptoms), their sustained use would, arguably, need to be guided and driven by internal working models (Jessop & Rutter, 2003).

Research within the CSM framework has shown that beliefs about the necessity of a treatment and concerns about the risks associated with it correlate with adherence to asthma preventer medications. Namely, Horne and Weinman (2002) found that treatment beliefs partially mediated the relationship between illness representations and adherence to asthma preventer medications. Moreover, they demonstrated that non-adherence was associated with greater doubts about the necessity of the medications, concerns about its potential side effects and perceived negative consequences of the illness.

In a recent position paper, Horne et al. (2007) argue that "…it may be possible for healthcare professionals to improve asthma control *[i.e., consistent use of inhaled corticosteroids]* by achieving a greater understanding of the patient's perspective" (p. 9). Certainly, exploring patients' illness models would facilitate understanding and improve current asthma education protocols. In fact, there have been efforts to target and alter patients' illness models to effect behavioural outcome. For example, Petrie, Cameron, Ellis, Buick, and Weinman (2002) conducted a brief hospital intervention for patients who had recently suffered a myocardial infarction (MI) that targeted individuals' negative illness perceptions (as assessed by the Illness Perception Questionnaire) to specifically alter beliefs about the timeline of recovery and consequences of having an

MI (e.g., that individuals would have to significantly reduce exercise activity over the long term). They found that those receiving the intervention returned to work faster and reported fewer symptoms at follow-up than those in the control group. Similarly, in a prospective study, Moss-Morris et al. (2007) found that illness representations changed as a function of a cognitive-behavioural intervention for pain, and that reductions in beliefs about the negative consequences predicted improved physical functioning and reductions in emotional representations and also found that an improved sense of coherence predicted psychological functioning.

While statistically significant, the correlations between treatment beliefs and adherence are quite modest, ranging from only .31 to .43 (Horne & Weinman, 2002). Why might beliefs, in and of themselves, account for no more than 21 percent of the variance in adherence? It may be because behavior is driven not only by patients' beliefs about the costs (e.g., side effects, inconvenience, and price) and benefits (e.g., immediate and long term symptom relief) of treatments, but also how i*mportant* each of the costs and benefits are to them.

This weighing of risks and benefits may be especially important for asthma preventer medications, which, while providing relief, also include a number of inhaled corticosteroids that may result in side effects (McTaggart-Cowan et al., 2008) and daily exposure to steroid medication. The decision to take preventer medications, therefore, involves balancing the probability of a desirable outcome (e.g., future symptom reduction) against that of an undesirable outcome (e.g., current and long term side effects). The health economic and marketing literatures provide useful frameworks for

examining the role that patient preferences may play in adherence to preventer medication.

**Assessing what Matters to Patients with Asthma**

The use of preference-based models in health care is relatively new. However, a few studies have applied a DCE paradigm to better understand the trade-offs patients with asthma are willing to make both in terms of symptoms as well as treatment. For example, McKenzie, Cairns, and Osman (2001) presented patients with moderate to severe asthma with a series of pairs of scenarios characterized by different combinations of symptoms, including cough, breathlessness, wheeze, chest tightness and sleep disturbance. Analysis of respondents' choices suggested that, as a group, participants saw cough as the most important symptom to target and reduce. The authors suggest that identifying patient preferences for symptom alleviation has important implications for treatment development.

In terms of treatment attributes, Haughney et al. (2007) administered a DCE to 147 patients with asthma. Based on qualitative interviews, the six attributes deemed most important for asthma self-management were: (1) symptom relief, (2) steroid dose, (3) asthma action plan, (4) management of acute exacerbations, (5) number of inhalers, and (6) response to deterioration. The overall relative importance of the attributes was assessed. As a group, participants were willing to trade some symptom relief for a simpler treatment regimen involving fewer inhalers and a lower dose of steroid.

Also using a DCE paradigm, McTaggart-Cowan and colleagues (2008) assessed patient preferences for various forms of asthma treatment. Participants were provided with scenarios which varied with respect to the degree of symptom free days, side effects

(i.e., the number of tremors/palpitations per month and oral thrush episodes per year), out of pocket costs, number of medications, and frequency of use per day. As did Haughney et al. (2007), they found that patients, as a group, were willing to trade symptom free days for a more convenient regimen with a decreased number of side effects.

With the introduction of the combination inhalers, however, new variables must be considered. For instance, the Symbicort and Advair combination inhalers require patients to carry only one inhaler (likely seen as an advantage by patients) yet it delivers a larger dose of corticosteroids than most stand-alone preventer inhalers (which might be seen as a disadvantage). In addition, for the "reliever" portion to work effectively, patients must also take their medications at set times each day, rather than "as needed", as per standard reliever medications. Therefore, preferences for steroid dosing, frequency of medication use and complexity (one versus two inhalers) must also be assessed.

**Knowledge, Beliefs and Preferences for Asthma: Can We Study Them Together?**

The Multiattribute Utility Model (MAU) is based on the premise that decisions are complex and that different factors are hierarchically weighted to influence ultimate behaviour (Chang, Chan, Chang, Yang, & Chen, 2008). This model provides a good framework for examining non-adherence to asthma medications for two reasons. First, it stipulates that many elements are incorporated into a decision. Second, it demonstrates that the elements influencing a decision form a hierarchical structure such that some are more important to the ultimate behaviour than others. For example, knowledge about asthma medications may not be as important to the decision making process as patients' preferences for treatment. The methodology adopted most typically by MAU researchers requires patients to explicitly state the importance of each category in their decision

making process. Given that patients could not be expected to have insight into the relative importance of their knowledge, beliefs or preferences in their decision making process, the methodology of MAU research is unsuitable for use in this study. The theory, however, offers a rationale for exploring the individual roles and combined effects of knowledge, illness and treatment beliefs and preference on adherence behaviour.

**Study Rationale and Hypotheses**

Although effective treatments for asthma have been developed and have been shown to reduce asthma morbidity and mortality (WHO, 2003), their utility is highly contingent on proper use by patients. That is, efficacy does not translate to effectiveness. This is why an understanding of factors governing adherence is a crucial element of health research. However, as Van Dulmen et al. (2007) have observed, adherence research over the last decade has remained largely atheoretical or driven by theories that are too circumscribed in scope.

As the previous review indicates, proper asthma preventer medication use may be driven by a number of factors, including the degree of *knowledge* about proper inhaler technique and asthma pathophysiology*, beliefs* about asthma and its treatment, and *preferences* for various health states and treatment regimens. Efforts to enhance patient adherence to preventer medication that take patient knowledge, beliefs, and preferences into account are likely to be more successful than those that do not and research on how these three elements work additively to produce adherence could be instructive. Unfortunately, to date, these three components have been studied in relative isolation, in the nursing, health psychology and health economics/medical decision making literature, respectively.

Accordingly, the proposed study will seek to integrate these three lines of research and model their additive effects on adherence behaviours. Specifically, it is predicted that:

*Hypothesis 1:* Increased knowledge about the pathophysiology of asthma will predict adherence to preventer medication.

*Hypothesis 2:* Beliefs about the chronicity of the disease, amount of control, severity of symptoms, sense of coherence and necessity of preventer medications will predict increased treatment adherence.

*Hypothesis 3*: Patient preferences will predict adherence. In particular, those who value long term outcomes will be more adherent to their preventer medications.

*Hypothesis 4:* Patient preferences for elements of their medication will predict adherence above and beyond that predicted by knowledge of their disease and beliefs about the disease and its treatment.

In addition, this study will extend the DCE methodology by generating preference parameters at a subgroup (rather than overall group) level. To my knowledge, this will be the second study in the adult health care domain (the first being Singh et al., 1998) to attempt to extract subgroup data from a conjoint analysis technique, and the first to apply the extracted data to predicting behavioural outcomes. Accordingly, an exploratory analysis will be conducted to assess the degree of convergence between patients' explicitly stated preferences (as measured by a standard 10 item rating scale) and their implicit preferences, as indicated by the discrete choice preference parameters and their differential effects on adherence.

The study was conducted in four phases: (1) Knowledge questionnaire modification, (2) Preference measure development, (3) In-field pilot study of questionnaires and, (4) Main study.

## Chapter II: Methods and Results of Phases 1 - 3

### Phase I: Knowledge Questionnaire Modification

This phase consisted of three stages: (1) Item modification and generation, (2) Assessment of item relevance and clarity, (3) Assessment of content validity.

**Stage 1: Item modification and generation**.

Currently, the most comprehensive self-report measure of asthma knowledge is the Asthma Knowledge Questionnaire developed by Schaffer and Yarandi (2007). The 24 item self-report, True-False measure taps the five content areas specified as necessary for asthma self-management by the National Asthma Education and Prevention Program: (1) Asthma pathophysiology, (2) Roles of medications, (3) Skills of inhaler use, (4) Environmental Controls, and (5) Rescue Medication Information. The total scale demonstrates a reasonable internal consistency of .69 (Schaffer and Yarandi, 2007).

In reviewing this measure with the consulting respirologist (C. Lisckai), however, it was apparent that knowledge of asthma pathophysiology, arguably the most important for understanding the rationale behind one's prescribed self-management regimen, was not adequately assessed in the original scale. Accordingly, four items pertaining to the pathophysiology of asthma either were generated or taken from other sources: *(1) Having swollen airways does not increase the risk of having an asthma attack (*F; New*), (2) During an asthma attack, the muscles around the airways tighten and the airways become narrow* (T; as per Allen & Jones, 1998)*, (3) Asthma is a disease that comes and goes* (F; New), and (4) *If asthma attacks stop, it means that the asthma has gone away* (F; as per Grant et al., 1999).

In addition, the questions on the original scale were worded in either personal (i.e., "you", "your") or general (i.e., "people") terms. We changed personal to general wording to increase the likelihood that responses to the items would tap global knowledge about asthma in general rather than reflecting the particulars of an individual's condition. Thus, items such as "*Keeping your bedroom windows open at night will help prevent asthma symptoms*" were changed to "*Keeping bedroom windows open at night will help prevent asthma attacks*". Finally, two items were eliminated. The first, "*Getting rid of cockroaches in your house may help your asthma*" was removed because it applies to densely populated cities and was deemed irrelevant for our sample, largely drawn from small to mid-sized urban and rural communities. The second, "*To use an asthma inhaler correctly, you need to breathe in as you press down on the inhaler*" was removed as our consulting physician deemed it inaccurate.

We also included an "Unsure" response option to discourage guessing, particularly by those prescribed single inhalers who thus might not be expected to have knowledge about combined inhalers.

The interim measure (Appendix A) consisted of 30 items that were then rated for relevance and clarity by a group of clinician experts (Phase 2). Based on their feedback, the scale was further altered and the 36 items of the revised scale were then rated by a group of graduate students for content validity (Phase 3). These stages are outlined below.

**Stage 2: Assessment of item relevance and clarity.**

***Method.***

*Participants.* A panel of approximately 35 respirologists, allergists, and/or asthma nurse educators from clinics across Ontario and Quebec were recruited by C. Lisckai, the consulting respirologist.

*Procedure.* Panelists, by means of an on-line survey, were presented with items from 6 content areas, including pathophysiology, medications and their effects, technique, symptoms, environmental triggers, and other asthma facts, purportedly covered by the survey. They were asked to rate the relevance/clarity of each item (1 = not relevant, 2 = confusing and cannot be assessed without revisions, 3 = relevant but requires minor changes, or 4 = succinct and relevant to content area; as per Schaffer & Yarandi, 2007). Space was also provided for written feedback.

***Results.***

Twenty-one of the thirty-five (a response rate of 60 percent) expert reviewers responded. The results are presented in Appendix A. All items received a mean rating above 3.32 (out of 4), suggesting that, on balance, they were deemed acceptable. Minor semantic modifications were made and conceptual issues were readdressed with the consulting physician (C. Lisckai). To enhance clarity, two items (#15 and #19) each were subdivided into two questions and one item (#23) was deleted because it was deemed inaccurate. Moreover, based on the panelists' comments, it was clear that more questions were needed to address knowledge about combination inhalers. As such, in collaboration with the consulting physician, the following two questions were added, (1) *A combination medication includes two types of medication to control asthma* (T)*, (2) A*

*person with asthma can use a combination inhaler for quick relief, even if they do not use it every day* (F). In addition, the symptom and technique subscales were deemed to need more items and so the following three questions were added: (1) *Chest tightness is a common symptom of asthma* (T), *(2) People with asthma get relief from their symptoms at night* (F), *(3) Asthma attacks often come on suddenly without any warning* (F).

The revised scale, consisting of 36 items, was then evaluated for content validity, as described below.

**Stage 3: Assessment of content validity.**

***Method.***

*Participants***.** Raters were 11 graduate students in psychology from the University of Western Ontario and Concordia University, ten of whom had training in survey design. The raters were not expected to have much previous knowledge about asthma and indeed rated themselves as only slightly knowledgeable (i.e., mean rating = 4.36 on a 10 point Likert scale, where 0 = no knowledge and 10 = extremely knowledgeable).

*Procedure.* The raters were presented with six content areas and descriptions of each (See Table 1, column 2) and were asked to indicate which of the six constructs each item was most consistent with. They were instructed to select "other" only if they were really unsure which category the item should be placed.

***Results.***

For an item to be considered indicative of a given content area, at least seven of the eleven raters had to place the item in its corresponding category. The items they rated pertaining to each category are presented in Table 1. The amount of agreement indicated

Table 1

*Knowledge Domain Descriptions and Questions*

| Domain | Description | Allocated Questions after Graduate Student Ratings |
|---|---|---|
| Pathophysiology | Physiology and functional changes associated with asthma and its acute exacerbations, and about the course of the disease in general. | 1. People with asthma can have swollen and inflamed airways even when they feel well. (T)<br>2. Asthma is a disease that does not last for a long time. (F)<br>3. It is possible for someone's asthma to be worse without them noticing a change in their breathing. (T)<br>4. Asthma can be cured. (F)<br>5. During an asthma attack, the muscles around the airways tighten and the airways become narrow. (T)<br>6. Having swollen airways does not increase the risk of having an asthma attack. (F)<br>7. When someone's asthma attack is over, it means that the asthma has gone away. (F)<br>8. Untreated asthma can cause death. (T)<br>9. If a person does not have asthma by age 40, they will never get it. (F) |

| Domain | Description | Allocated Questions after Graduate Student Ratings |
|---|---|---|
| Medication and Effects | Purpose and effects of asthma medications. The three types of asthma medication include: (1) Inhaler steroid (controller) medications- used to prevent asthma attacks; (2) Quick relief medications- used to relieve an asthma attack once they begin; (3) Combination inhalers- combine control and relief medications in one inhaler. | 1. Quick relief medications should be taken every day, even if people are feeling well. (F)<br>2. Inhaled steroids (controller medications) prevent asthma attacks. (T)<br>3. People with asthma should wait until their symptoms are really bad before using a quick relief medication. (F)<br>4. A person with asthma can use a combination inhaler for quick relief, even if they do not use it every day. (F)<br>5. Taking an antibiotic such as penicillin will help most bad asthma attacks. (F)<br>6. People may not notice improvements in their breathing for 1-4 weeks after they start using inhaled steroids. (T)<br>7. The purpose of steroid medication inhalers is to stop an asthma attack when it happens. (F)<br>8. People with asthma can usually help control their symptoms by taking the appropriate medications. (T)<br>9. It is okay to take inhaled steroids (controllers) only when people notice their symptoms getting worse. (F)<br>10. Inhaled steroids will relieve an asthma attack within 20 minutes. (F) |

| Domain | Description | Allocated Questions after Graduate Student Ratings |
|---|---|---|
| | | 11. People with asthma do not need to take their daily inhaled steroids (controller) if they feel well. (F) |
| | | 12. A combination inhaler includes two types of medication to control asthma. (T) |
| Technique | The way technical skills and procedural information needed to effectively use an asthma inhaler. | 1. People with asthma should try to hold their breath for 8-10 seconds after each puff of their inhaler. (T) |
| | | 2. People with asthma should rinse and gargle after each use of their inhaled (controller) steroid. (T) |
| | | 3. People with asthma should wait about one minute between puffs of their quick relief medication. (T) |
| | | 4. People with asthma should breathe out partially, but not fully, just before taking their medication. (F) |
| Environmental Triggers | Environmental conditions (e.g., irritants, allergens) that can worsen asthma symptoms. | 1. Molds can trigger asthma symptoms for some people. (T) |
| | | 2. Being around others who smoke does not bother a person's asthma, so long as they do not smoke themselves. (F) |
| | | 3. Cold air can make asthma symptoms worse. (T) |
| | | 4. People can usually help control their symptoms by avoiding things (triggers) that make their asthma worse. (T) |

| Domain | Description | Allocated Questions after Graduate Student Ratings |
|---|---|---|
| | | 5. People with asthma should avoid exercise.(F) |
| | | 6. Keeping bedroom windows open at night will help prevent asthma attacks. (F) |
| Symptoms | Changes in the body or its function experienced by the patient and indicative of disease. | 1. Frequent coughing can be a symptom of asthma. (T) |
| | | 2. Asthma may cause wheezing during exercise. (T) |
| | | 3. Chest tightness is a common symptom of asthma. (T) |
| | | 4. People with asthma get relief from their symptoms at night. (F) |
| | | 5. Asthma attacks often come on suddenly without any warning. (F) |
| Other | Information about asthma that does not fit into any of the other five categories. | None |

good content validity, and so the version rated by the students was not altered further. Accordingly, the final scale (See Appendix B) consisted of 36 items, with nine in the disease category, 12 in the medication category, 4 in the technique category, 6 in the environment category, and 5 in the symptoms category.

## Phase II: Development of the Preference Measures

### Method.

#### *Discrete choice scenarios.*

McKenzie, Cairns and Osman (2001) stipulate that the process of creating discrete choice scenarios involves a series of steps. These steps include: (1) Identifying the attributes important to the population in question, (2) Reducing the scenarios to a manageable number of combinations, and (3) Deciding how to establish preferences based on the selected scenarios. As per previously conducted DCEs in health care (Lanscar et al., 2007), the attributes and their levels adopted for this study reflected common variations in asthma treatments and their outcomes, informed by consultations with two respiratory specialists (C. Lisckai and N. Patterson), a thorough literature review and perusal of asthma treatment guidelines. The factors were then culled to the seven pertaining most directly to the study's main questions. All (binary) attribute levels were plausible and clinically relevant. The attributes and their levels were as follows:

1. Long-term outcomes (Asthma will be the same in 10 years *versus* worse in 10 years)
2. Short-term consequences (Fewer asthma attacks over next six months *versus* the same number of attacks over the next six months)
3. Immediate effects (Relief within 5 minutes *versus* Relief within 30 minutes)

4. Side-effects (Major/ Long-term *versus* Minor/Short-term*)*

5. Fixed dosing (Every day at set times and more if I need it *versus* Only when needed)

6. Number of Inhalers (1 *versus* 2)

7. Dose of Steroid (High *versus* Low)

Given that DCEs applied to consumers' health care decision-making have involved as many as 12 factors (Lanscar & Louviere, 2008), the cognitive load for participants imposed by a seven-factor manipulation was deemed reasonable.

The most common DCE design involves factors each having only two levels, thus referred to as a 'binary attribute design'. To keep the design and resultant data analysis reasonable, the binary approach was used here as well. Although a limitation of the binary attribute design is that it cannot generate non-linear effects, it can estimate main factor effects, thereby capable of providing meaningful information (Street & Burgess, 2007). The present study is unique in that unlike previous DCE studies applied to asthma or its treatment, these scenarios captured treatment features (complexity and frequency) that differentiate combination therapy from regular asthma treatments.

***Rating scale development.***

To date, the standard approach to eliciting patient preferences is for participants to rate individual attributes with respect to their importance (Phillips, Johnson, & Maddala, 2002; Ryan et al., 2001; Singh et al., 1998). To compare information derived from these rating scales with those from DCEs, we generated items that captured the attributes of interest and wrote instructions designed to encourage participants to think about the "trade-offs" involved in making a decision about taking a medication. The intent was for

these rating scales to explicitly gauge the variables assessed more implicitly in the discrete choice experiments. The instructions read: "*There are different things people have to weigh when deciding whether or not to use an inhaler. For example, while some people with asthma may worry about a medication's side effects, they feel that the benefits from the medication are worth the risk. Others are not so sure. We are interested in what kinds of things you consider when deciding whether or not to use an inhaler. Trying to keep the list of things below in mind, for each item, please circle on the scale the number that best describes the importance of each of the following*." The scale was designed such that 1 = Least important and 10 = Most important. Items included: (1) The number of inhalers I need to take, (2) Having to take an inhaler every day, (3) Being able to take an inhaler only when I need it, (4) Possible short-term side effects of the inhaler, (5) Possible long-term side effects of the inhaler, (6) Risk of addiction from the inhaler, (7) The inhaler can take my symptoms away within minutes, (8) The inhaler can help keep my asthma from getting worse over the next 10 years, (9) The inhaler can reduce how often I get asthma attacks over the next 6 months, (10) The cost of the inhaler. The scale is presented in Appendix C.

**Results.**

The scenarios were developed for a partial factorial design. Seven attributes each with two levels (i.e., $2^7$) yielded 128 permutations. By means of SPSS ORTHOPLAN and Addelman's formula (1962), the scenarios were culled into 8 orthogonal scenarios. Using the "shifted-set" method (Chrzan & Orme, 2000), another 8 scenarios were generated and paired to create the choice sets. The sets met the three criteria for generating a DCE (McTaggart-Cowan et al., 2007), namely: (1) *orthogonality*, to ensure

a minimum amount of overlap between the attributes, (2) *level balance*, so that all levels occurred with equal frequency, and (3) *minimum overlap*, such that no attribute appeared twice within the same choice set. Moreover, care was taken to ensure that all level combinations were plausible treatment options.

The choice sets and instructions are presented in Appendix D.

## Phase III: In-Field Feasibility Study

### Method.

To ensure that the DCE task and self-report measures were comprehensible to the target population, a pilot study was conducted. All procedures were approved by the University of Western Ontario Health Sciences Review Board (Protocol # 16500E, Appendix E).

#### *Participants.*

All consecutive patients over the age of 18 attending the asthma clinic reporting that they could understand written English were invited to participate. Of the roughly 70 individuals approached, 56 (for a response rate of 80%) individuals consented to participate.

#### *Measures.*

*Asthma Knowledge Questionnaire.*

This self-report measure developed in Phase I (See Appendix B) consisted of 36 items assessing participants' knowledge across five domains: (1) Pathophysiology of the disease, (2) Knowledge of Medication, (3) Technique, (4) Environmental Triggers, and (5) Asthma symptoms. Participants were asked to record the extent to which they

believed each item was true or false. There was an "unsure" option to discourage guessing.

*Discrete Choice Experiment (DCE) measure.*

Participants were presented with the same eight discrete choice sets (16 scenarios) developed in Phase II (Appendix D) which varied along the seven factors relevant to the study hypotheses.

*Rating scales.*

Participants were presented with the 10 item rating scale developed in Phase II (Appendix C) with the preamble described above. To ensure that overt ratings did not influence more implicit ratings associated with the DCE, half the participants were given the rating scales before completing the DCE and half were given the rating scale after completing the DCE.

*Demographic and health history information.*

Self-reported demographic and health history information was collected on gender, age, years of education, years with asthma and the frequency of asthma-related medical visits over the past year.

***Procedure.***

Once participants arrived at the asthma clinic they were asked by the receptionist if they would be willing to hear about a research study. If they agreed, a research assistant approached patients in the waiting area and went through the informed consent procedure. Those who consented were asked to complete the knowledge questionnaire, discrete choice scenarios, demographics page and rating scales while waiting to see their physician. This took approximately 10 minutes.

## Results.

### *Demographic information.*

Participants' demographic information is presented in Table 2. The average age was 46 years and 65% were female. Over 50% reported some college or university education. This was the first asthma clinic visit for 30% of the sample. They had carried their asthma diagnosis for an average of 21.64 (*sd* = 14.82, range = 1 – 57) years and reported having visited an emergency room an average of 1.3 times over the previous year for asthma-related concerns.

### *Knowledge questionnaire.*

Participants' knowledge of the pathophysiology of asthma, asthma medications and inhaler technique were all normally distributed. The normality statistics for the subscales are presented in Table 3. Knowledge with regards to both environmental triggers as well as asthma symptoms was significantly negatively skewed. Total scores were normally distributed, suggesting that participants had a range of knowledge about asthma and its management. The percentage of participants responding correctly is presented in Appendix F. One item, *Asthma attacks often come on suddenly without any warning symptoms*, was responded to incorrectly by 80% of the participants. In consultation with clinic staff, it was decided that the wording of the question was ambiguous and the item was removed from the scale.

The total scale was not internally consistent ($\alpha = .40$), nor were the subscales (all $\alpha$'s $< .52$; See Table 3). However, one would not necessarily expect pockets of information to hang together. Accordingly, the knowledge subscales were retained.

Table 2

*Demographic Information of Participants in Pilot Study*

| | N (%) | M (SD) | Observed Range |
|---|---|---|---|
| **Demographics** | | | |
| Age | 52 | 46 (16.80) | 18 - 85 |
| Years of education | 55 | 4 (1.26) † | 1-6 |
| Years with asthma diagnosis | 44 | 21.64 (14.82) | 1 - 57 |
| **Health Care Use Variables** | | | |
| Attendance at Clinic | 56 | | |
| First Visit | 18 (30) | - | - |
| Second Visit | 7 (11.7) | - | - |
| Third Visit | 5 (8.3) | - | - |
| Greater than 3 visits | 26 (42.3) | - | - |
| Family doctor visits in past year for asthma related concerns | 56 | 2.52 (3.04) | 0-12 |
| ER visits in last year for asthma related concerns | 56 | 1.30 (2.16) | 0 - 10 |

† 1 = Completed grade 8, 2 = Some high school, 3= Completed high school, 4 = Part college/University, 5 = Completed college or university, 6 = Graduate school

Table 3

*Descriptive Data for Knowledge Subscales from Pilot Study Sample*

| Scale | N of Items | *M*[a] | *SD* | Cronbach's α | Skew | Kurtosis |
|---|---|---|---|---|---|---|
| Pathophysiology | 9 | 2.74 | .22 | .31 | -.72 | -.42 |
| Medication | 12 | 2.39 | .27 | .45 | -.37 | -.78 |
| Technique | 4 | 2.64 | .32 | .12 | -.47 | -.65 |
| Symptom | 4 | 2.87 | .24 | .52 | -2.17 | 4.84 |
| Environment | 6 | 2.84 | .20 | .14 | -1.05 | .08 |
| Total Scale | 35 | 2.61 | .16 | .40 | -.70 | .57 |

*Note*. N = 56.

[a]1 = Incorrect, 2 = Unsure, 3 = Correct.

***Discrete choice experiments.***

Participants reported that they understood what they generally were being asked to do for the DCE and their behaviour during the task seemed to bear this out. However, participants were confused by the long-term outcome option, in which they were asked to decide whether or not they would choose their *asthma* to be the same or worse in 10 years, not knowing whether to term referred to pathophysiology (as intended) or symptoms. Accordingly, in the final version of the task, the term *asthma* was replaced with *airways*.

***Rating scales.***

Participants stated to the research assistant that they understood the explicit rating task. Given that we were asking participants to rate their preferences both implicitly (through the use of DCEs) and explicitly (through the rating scale) we wanted to ensure that one rating was not affecting the other. Accordingly, MANOVA analyses were conducted on the rating scale items to assess whether those participants who completed the DCEs before the ratings had significantly different ratings on the scales than those who completed the DCEs after the ratings. The analysis was non-significant, $F(10,43) = 6.99$, *ns*, indicating that there were no group differences on the rating items whether the DCEs were given before or afterwards. Similarly, a MANOVA on the implicit (i.e., DCE) scores revealed no order effect, $F(7,48) = 1.95$, *ns*.

# Chapter III: Method for Main Study

## Participants

One hundred and forty individuals between the ages of 19 and 82 ($M$ = 45.29, $SD$= 15.97) with a diagnosis or possible diagnosis of asthma were recruited from the Asthma Centre at St. Joseph's Hospital in London, Ontario. The Centre is a tertiary care facility serving adults outpatients. It receives approximately 30-40 % of its referrals from the local emergency department, approximately 40 % from general practitioners, and the remainder from various specialists' offices. As such, it treats individuals with varying levels of asthma severity. As standard practice, patients are seen by either a respirologist or an allergist during their first visit and are seen by the other specialty during their second visit. Patients found to have a primary diagnosis of another respiratory condition are referred to the appropriate clinic (e.g., venom and allergy, the chronic obstructive pulmonary disease clinic, etc.).

All patients over 18 years of age, who had sufficient comprehension of written English and were prescribed a preventer medication, were approached to participate. Patients with significant other lung diseases (e.g., Chronic Obstructive Pulmonary Disease, emphysema, lung cancer, vocal cord dysfunction) were excluded from the study.

The study was approved by the University of Western Ontario Health Sciences Review Board (Protocol # 16869E, Appendix G). Participants read a letter of information, signed an informed consent form (Appendices H and I, respectively) and received a total of $50.00 for their participation, paid in intervals based on study completion. Funding was provided by the Canadian Institutes of Health Research (CIHR-CGD Fellowship 87781: Awarded to N. Gryfe).

## Measures

### Asthma Knowledge Questionnaire.

The self-report measure used in this study was a modified version of the recently developed Asthma Self-Management Questionnaire (Schaffer & Yarandi, 2007). The current 35 item self-report scale was based on the expert panel ratings as well as the content validity ratings, as described earlier. Participants were asked to indicate whether they believed each item was true or false. An "unsure" option was also given.

### Beliefs about illness.

The most widely used quantitative measure of illness cognitions is the Illness Perception Questionnaire- Revised (IPQ-R; Moss-Morris et al., 2002), which has three sections: The first section, an 'identity' subscale, consists of 14 common symptoms (e.g., *pain, nausea, upset stomach, breathlessness*). Respondents are asked both to indicate the extent to which they are bothered by each symptom and to indicate whether they think each of the symptoms they have endorsed are related to the illness in question (asthma). The instructions for this scale were modified slightly to increase clarity for the reader.

The second section is comprised of 50 items rated by the respondent on 5 point Likert-type scales (1 = strongly disagree 5 = strongly agree). Items include statements about the consequences of asthma for patients (e.g., *My illness has major consequences on my life*), the extent to which it makes sense to them (e.g., *My condition is a mystery to me*) and causes them emotional distress (e.g. *When I think about my condition I get upset*). Moreover, they are asked about the perceived timeline (e.g., *My condition will last a long time*), personal controllability (e.g., *There is a lot which I can do to control my*

*illness*) and treatability (e.g., *My treatment will be effective in curing my condition*) of their asthma.

The third section, an 18 item cause subscale, includes common causes of illnesses (e.g., *germ or virus, heredity, my own behaviour*). The authors encourage a tailoring of the measure to the illness in question (Moss-Morris et al., 2003) and, as such, two asthma-specific causes were included: *1. A physical problem with my breathing airways, 2. My sensitivity to physical changes in my breathing airways*.

Prior research (Moss-Morris et al., 2002) has shown the subscales to have good internal reliability with Cronbach's alphas ranging from .79 for the cyclical timeline dimension to .89 for the timeline chronicity. Previous data collected in our lab indicate similarly high internal consistencies with asthma patients, the one exception being the treatment control subscale ($\alpha = .33$). One possible explanation for this low score is that the treatment control subscale was designed as a broad based measure to gauge perceived efficacy of a variety of medications and thus is not sufficiently nuanced to distinguish between perceptions of different classes (i.e., preventer versus recue) of asthma medications. Given our specific interest in perceptions of preventer medication, the necessity scale of the beliefs about treatment scale (see below) was taken as the index of perceived preventer medication efficacy.

**Beliefs about treatment.**

The Beliefs about Medicines Questionnaire- Asthma Specific (BMQ) is a 14 item self-report Likert-type scale (1 = strongly disagree to 5 = strongly agree) that taps patients' concerns about the potential adverse effects of preventer medications as well as their doubts about the necessity of taking the medication (Horne, Weinman, & Hankin,

1999). Ten of the fourteen items assess beliefs that can apply to a range of chronic illnesses, and four items specific to asthma medication were later added by Horne and Weinman (2002). Sample items include: "*This inhaler is the most important part of my asthma treatment*" (necessity) and "*People who use these inhalers should stop their treatment every now and again*" (concern). The treatment concern and necessity subscales have adequate internal consistency (α's =.71 and .82, respectively). Scoring is such that higher values on the treatment concern subscale indicate more concern about adverse effects and higher scores on the treatment necessity scale indicate stronger beliefs about the importance of the medication for their management. Participants completed this measure not only with reference to their preventer medication but also with reference to rescue inhalers, as we reasoned that beliefs about the necessity for and concerns about this class of medication might also influence the use of preventers. The presentation of these measures was counterbalanced.

**Preference tasks.**

***Discrete Choice Experiments (DCE).***

Discrete choice scenarios were designed specifically for this study. Participants were presented with 8 choice sets (16 scenarios) that varied along 7 dimensions, each with two levels (See Appendix D). The pilot study (Phase III) confirmed that the cognitive load for participants was not too large, consistent with work in the area which suggests that 8 or 9 choice sets can be effectively processed (Street & Bourgess, 2007).

***Rating scales.***

Respondents were asked to rate 10 items (created specifically for this study) pertaining to asthma treatment (e.g. side-effects, cost, long-term effects, etc.) on a scale

of 1 (least important) to 10 (most important). The instructions encouraged participants think about the "trade-offs" involved in making a decision about taking a medication. The rating scales are presented in Appendix C.

**Medication adherence.**

***Medication Adherence Report Scale (MARS).***

Measurement of adherence is controversial and fraught with methodological limitations. For example, electronic monitoring as well as biochemical data can be prohibitively costly and pharmacy data is logistically difficult to obtain (Rau, 2005). In addition, while self-report measures tend to be the most widely-used measures in research, they have been found to underestimate non-adherence by approximately 20 percent (Horne & Weinman, 1999), probably because patients are loathe to admit (to themselves and others) that they do not follow their health care providers' prescriptions. Self-report measures, however, are easily implemented and allow for the examination of behavioural and psychological processes that underlie adherence behaviour (Mora et al., 2011; Wroe, 2002).

The Medication Adherence Report Scale (MARS) is a self-report measure of adherence designed to measure respondents' tendencies that impede the regular use of prescribed medications (Cochrane et al., 1999). Different versions of the MARS for asthma have been studied, but research suggests that behaviours as assessed by both the full (10 item) and short (5 item) version of the scale to be significantly correlated with more objective measures of adherence such as electronic monitoring (Cohen et al., 2008; Ohm & Aaronson, 2006) and pill counting (Menckeberg et al., 2008).

In this study, a nine-item self-report measure, using a five point (ranging from 1 = always to 5 = never) Likert-type scale was administered to assess adherence (Horne & Weinman, 2002). The 9 items scale was selected as it has been validated for use in other studies measuring illness beliefs along with adherence (Horne & Weinman, 2002). The scale demonstrated good internal validity ($\alpha = .85$ and a single factor principal component analysis accounting for 88.7% of the variance) and good criterion validity when compared to electronic monitoring, and strong construct validity (Cohen et al., 2008). In addition, Cohen et al. (2008) found that patients who claimed to use inhaled corticosteroids even when they were not symptomatic were more likely to classified as adherers by the MARS for asthma as were those who responded that their inhaled corticosteroid medication was a controller medication.

Following the suggestion of Rand and Wise (1994), the MARS was administered with the following preamble, aimed at promoting a non-defensive mindset: "*Many people find a way to use their inhaler preventer medicine which suits them. This may differ from the instructions on the label or from what their doctor had in mind. Here are some ways in which people have said they use their medicines. For each statement, circle the number which best applies to you*". By focusing on non-adherence, rather than compliance with practitioner instruction, the preamble purportedly makes it easier for respondents to report acts that interfere with the 'proper' use of their preventer medications.

To further minimize social desirability, many of the items are worded to refer to non-adherent behaviour (e.g., "*I alter the dose*"), rather than adherent behaviours *(e.g. I take the dose as prescribed)* (Cohen et al., 2008) because reports of non-adherence tend

to be more accurate than reports of adherence (Haynes et al., 1980). Horne and Weinman (2002) reported that 73.2% of asthma patients reported that they sometimes, often or always, engaged in one of the eleven non-adherent behaviours assessed by the MARS. These levels of non-adherence are similar to levels of non-adherence to asthma medications found in other studies that have used more "objective" measures of adherence such as tablet count and drug serum assays (e.g. Bosley, Fosbury, & Cochrane, 1995; Horne & Weinman, 2002).

To ensure participants were thinking about their preventer (and not rescue) medications while answering the questions, they were instructed to write down the name of their preventer medication at the top of the questionnaire. Scores for each item were summed to give a total score ranging from 9 – 45, with higher scores indicating greater adherence.

***Medication diaries.***

To assess the frequency with which patients used their rescue and preventer medication, participants completed a daily medication log. A sample of the medication diary is presented in Appendix J. Although Oldenmenger et al. (2007) demonstrated patients' ability to complete medication diaries each day for 28 days, so as to encourage full study participation patients were asked to complete these logs only for the first week following their appointment and for a full week four weeks later. Participants prescribed combination inhalers (which contain both preventer and rescue medication) were instructed to record any additional puffs that they took for relief purposes in the rescue medication space provided.

***Dose counter***.

Many preventer medications are equipped with a mechanism that counts down the remaining inhaler doses. While this does not indicate whether patients are taking their medications *when* they are supposed to, it theoretically provides an inexpensive and objective measurement of the number of doses taken. Accordingly, participants were asked to record the "number on their inhaler" at the end of each week's treatment diary. Unfortunately, even though this procedure was clearly explained to participants and we encouraged participants to ask questions, the data obtained from this measure ultimately were unusable. This is both because some participants confused the dose counter with the dosage accompanying the brand of medication (e.g., Advair *500*mg, Symbicort *200*mg) and because the dose counters on the combination inhalers do not record each administration of the medication, but rather, demarcate blocks of 10 or 20 doses.

**Individual difference variables.**

***Demographic information.***

Participants provided information about their gender, age, annual household income, years of education, relationship status, years with asthma and the frequency of asthma related medical visits over the past year (Appendix K).

***Patient enablement.***

Patient enablement was gauged by the Modified Patient Enablement Instrument for asthma patients (Haugney et al., 2007). The scale is a 6 item Likert-type self-report measure in which patients rate (from 0 = Same, less or not applicable to 3 = Much better) their perceived ability to cope with and participate in their own care as a consequence of a medical encounter. For the purposes of this study, the rating scale was changed to a 5

point scale (where 0 = Not applicable, 1 = Less, 2 = Same, 3 = Better, 4 = Much Better). Sample items include "*Able to cope with life*" and "*Confident about your health*". The measure is highly internally consistent (α = .92).

***Patient satisfaction.***

The Satisfaction Questionnaire (Jackson, Kincey, Fiddler, Creed, & Tomenson, 2004) is a 15 item self-report measure that assesses how satisfied patients are along four dimensions: (1) patient-provider interaction, (2) information given to them by their provider, (3) their health (4) the health care environment. The satisfaction with the environment subscale was omitted for the purpose of this study. All subscales have been validated and the summed scores demonstrate excellent levels of internal consistency (α = .94).

***Quality of life.***

The Asthma Quality of Life Scale- Mini Version (Juniper, Guyatt, Cox, Ferrie, & King, 1999) is a disease-specific instrument comprised of 15 items, grouped into four domains: (1) asthma symptoms, (2) responses to environmental stimuli, (3) limitations in activities, and (4) emotional dysfunction. Respondents are presented with a 7 point Likert-type scale on which they are asked to rate their degree of impairment (1 = Greatest impairment to 7 = Least impairment). The AQLQ-mini has been demonstrated to be reliable (ICC = .83) and is a valid measure of asthma quality of life.

***Panic-Fear.***

The Panic-Fear Subscale of the Asthma Symptom Checklist (Ritz, Bobb, Edwards, & Steptoe, 2001) is a 7 item, Likert-type (where 0 = Never and 4= Always) scale assessing patients' emotional responses (being frightened, afraid, or worried) during

an asthma attack. The scale demonstrates excellent internal consistency (Cronbach's α = .94).

***Positive and Negative Affect Schedule (PANAS).***

The PANAS (Watson, Clarke, & Tellegan, 1988) is a 20-item self-report questionnaire in which participants rate, on a five-point Likert-type scale (where 1 = very slightly or not at all and 5 = extremely) the extent to which a range of emotional adjectives such as "*enthusiastic*", "*excited*", "*distressed*" and "*nervous*" describe them in general. The PANAS generates two subscale scores: Negative Affect and Positive Affect. Each subscale demonstrates good internal consistency and test-retest reliability.

**Procedure**

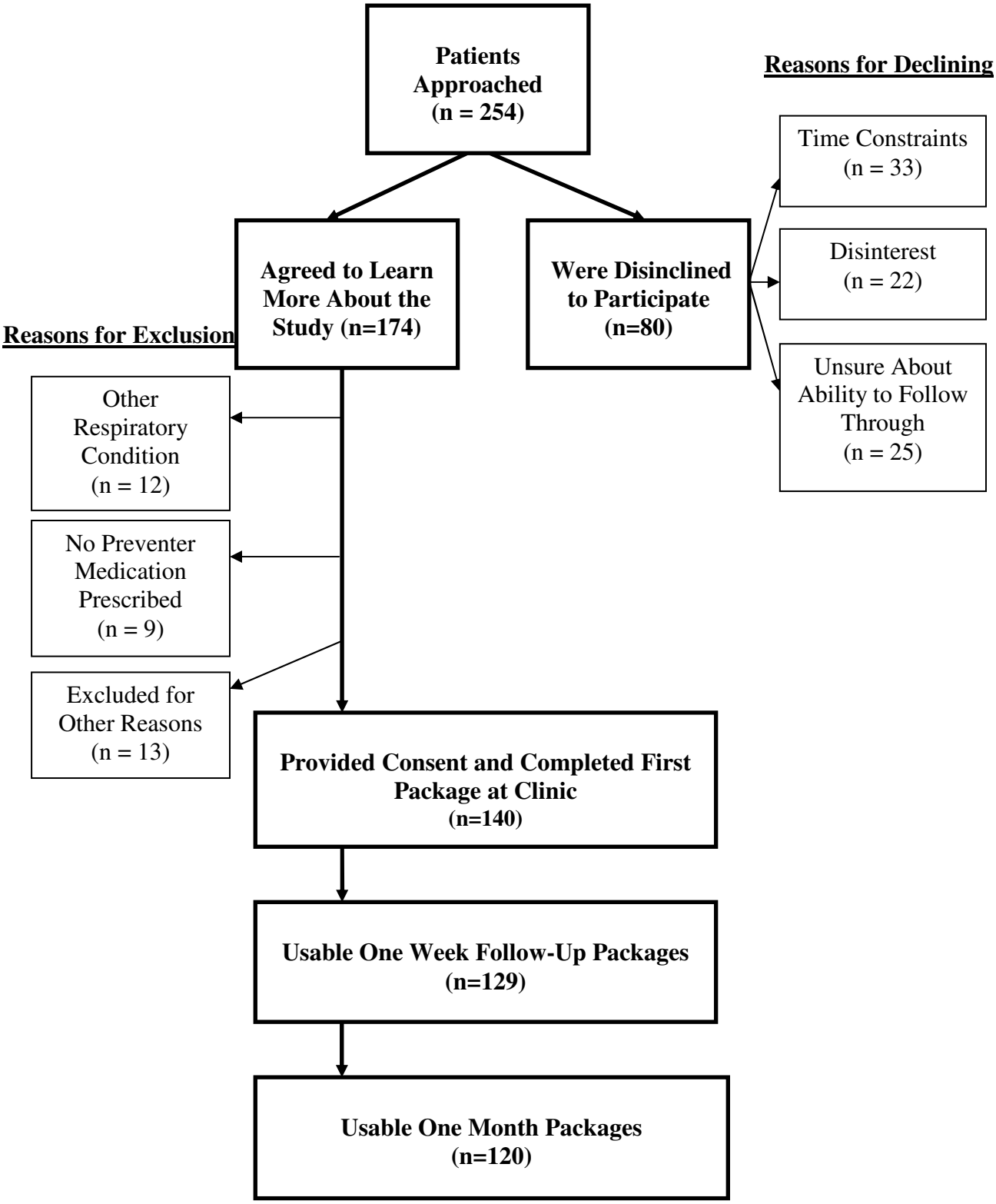
For ease of presentation, the following elements of the protocol will be presented chronologically: (1) Recruitment, (2) Pre-clinical encounter, (3) Post-clinical encounter, and (4) Follow-up.

**Recruitment.**

Upon arrival at the clinic, those patients who met the eligibility criteria were asked by the receptionist if they would mind being approached about a research study under way at the clinic. Two hundred and fifty four patients (119 new clinic patients and 135 patients returning for follow-up visits) were approached to participate, given a verbal overview of the study and asked to read over a letter of information. Figure 1 illustrates the recruitment procedure and consent rates for the study participants. One hundred and seventy four patients (68%) consented. The primary reasons cited by those who declined to learn more about the study were time constraints ($n$ = 33), disinterest ($n$ = 22) and

Figure 1

*Flow of Participants Through Study*



concerns that they would not follow through ($n$ = 25). Of the 174 who consented, 34 subsequently did not meet eligibility requirements, leaving 140 participants, 11 of whom did not complete the one-week post-appointment questionnaires. An additional nine did not submit the one-month post appointment measure. Accordingly, complete data were available for 120 participants.

**Pre-clinical Encounter.**

Once eligibility criteria were established and patients consented to the study, while waiting for their pulmonary function test, participants were asked to complete a booklet containing the demographics information questionnaire, the Asthma Quality of Life Measure (AQLQ), the Positive-Negative Affect Scale (PANAS), the Panic-Fear Scale, and the Medication Adherence Report Scale (MARS). Those who did not have time to complete these measures before the pulmonary function test finished them afterwards while waiting to see their physician or nurse.

**Post-clinical Encounter.**

Following the clinical visit, patients were asked to complete the Discrete Choice Experiment Task (DCE), the Illness Perception Questionnaire (IPQ-R), the Beliefs about Medicines Questionnaire (BMQ), the Asthma Knowledge Questionnaire and the preference rating scales. To mitigate against respondent fatigue, participants were given the patient satisfaction and enablement scales to complete at home along with the first seven day treatment diary. The diary also included a space for them to indicate the dose count from their inhaler (though, as noted earlier, these data were not included in the analyses).

Patients had the option of completing the satisfaction and enablement measures as well as the treatment diary online, and, if so inclined, were instructed on how to do so. Those choosing to complete hard copies of these measures were given a return-addressed postage paid envelope. The researcher ensured that participants understood the instructions for all take-home measures. They were reimbursed $10 for their time and additional parking expenses.

**Follow-Up.**

The 61 participants who completed the follow-up portion of the study by mail were contacted three weeks following their appointment by telephone to remind them that a medication diary, a copy of the MARS, and an AQLQ would arrive shortly by mail. Included in the package was a return-addressed postage-paid envelope as well as instructions to start completing the MARS and AQLQ and diaries the evening they received the package.

The 79 participants completing the follow-up portion of the study online were sent an email one month after their appointment to ensure they were prompted at the same time as those who chose the mailing option. The email included links to the AQLQ and MARS as well as the daily records. Participants were instructed to complete the AQLQ and MARS on the evening that they began the records.

Participants were compensated for the portion of the follow-up study they had completed ($20.00 for each of the two-week records) once their final packet was received.

Once all data were collected, participants' prescription regimens were extracted from their clinical records by an administrative clerk employed by the hospital.

Moreover, a nurse educator affiliated with the asthma clinic reviewed patients' clinical files to confirm that they did indeed have asthma, which they all did.

**Statistical Analyses**

Statistical analyses were carried out using PSAW 18 and LatentGold 4.5 software packages.

Relationships between the predictor and outcome variables were examined using Pearson and Spearman correlation coefficients, as appropriate. Preference data were explored through latent class analysis.

The contributions of knowledge, beliefs and preferences individually on adherence were evaluated using simple linear regressions. The relative contribution of each of these variables as predictors of adherence was assessed using a hierarchical linear multiple regression analysis, with reported MARS scores as well as diary reports as the dependent variables and predictors entered in the following order: 1. Knowledge of the pathophysiology of asthma; 2. Illness beliefs and Treatment Beliefs and 3. Treatment preferences. All study analyses were repeated to determine whether there was a main effect of gender or previous experience at the clinic (i.e., number of prior clinic visits) and whether inclusion of these variables as co-variates altered the findings. No such effects were observed.

# Chapter IV: Results

## Sample Demographics

The demographic and asthma-related characteristics of the sample are presented in Table 4. The majority of the sample (69%) was female. On average, participants had been diagnosed with asthma at age 24 (*SD* = 18.71). The majority (74%) had visited their family doctor for respiratory related issues at least once in the previous year, with the mean number of visits close to three. Fifty-three percent had visited the emergency room for respiratory related symptoms at least once in the previous year.

The criteria for normal distribution adopted for the study were a skew between -3 and +3 (see Kline, 2009) and kurtosis less than 2.58, as recommended by Field (2009). All demographic variables were appropriately distributed, with the exception of participants' asthma related visits to their family physician and ER related visits. That is, these distributions peaked at 0, as 27 % of participants stated that they had not gone to see their family doctor in the past year and 47 % stated they had not visited the ER. These patterns of health care use statistics are similar to those reported by other community- managed asthma patients (Horne & Weinman, 2002).

At the point at which they were recruited into the study, 46% of participants were attending the asthma clinic at St. Joseph's Hospital for the first time, with the remainder (54%) attending for a follow-up visit. The majority (78.5%) had been prescribed a combination medication inhaler as part of their asthma treatment regimen.

The demographic characteristics of those completing the follow-up questionnaires and diaries by mail (44% of the sample) did not differ (as per independent samples *t*-tests

Table 4

*Participant Characteristics*

| | N (%) | *M (SD)* | Observed Range | Skew | Kurtosis |
|---|---|---|---|---|---|
| **Demographic Information** | | | | | |
| Age | 135 | 45.39 (15.97) | 19 - 82 | .19 | -1.02 |
| Age at diagnosis | 127 | 24.04 (18.71) | 0 - 68 | .59 | -.72 |
| Years of education | 138 | 14.98 (3.31) | 4 - 25 | -.25 | 1.38 |
| Household income[a] | 125 | 3.30 (1.74) | 1 - 6 | .15 | -1.26 |
| Employment status[b] | 138 | 6.13 (2.73) | - | - | - |
| Employed (Full time) | 53 (37.9) | - | - | | |
| Working from Home | 4 (2.9) | - | - | | |
| Employed (Part time) | 25 (10.7) | - | - | | |
| Homemaker | 4 (2.9) | - | - | | |
| Student | 8 (5.7) | - | - | | |

| | N (%) | *M (SD)* | Observed Range | Skew | Kurtosis |
|---|---|---|---|---|---|
| Retired | 26 (18.6) | - | - | | |
| On Disability | 15 (10.7) | - | - | | |
| Unemployed | 6 (4.3) | - | - | | |
| Other | 7 (5) | - | - | | |
| **Health Care Use Variables** | | | | | |
| Attendance at Clinic | 140 | | | .48 | -1.42 |
| First Visit | 64 (45.7) | - | - | | |
| Second Visit | 13 (9.3) | - | - | | |
| Third Visit | 20 (14.3) | - | - | | |
| Greater than 3 visits | 43 (30.7) | - | - | | |
| Asthma related visits to family physician (in past year) | 140 | 2.89 (3.35) | 0 - 24 | 2.50 | 10.87 |

| | N (%) | *M (SD)* | Observed Range | Skew | Kurtosis |
|---|---|---|---|---|---|
| Asthma related visits to ER (in past year) | 140 | 1.49 (2.06) | 0 - 12 | 2.06 | 5.82 |
| **Quality of Life Variables** | | | | | |
| AQLQ | 140 | 3.71 (1.22) | 1 - 7 | -.01 | -.60 |
| **Prescribed Medications** | | | | | |
| Combination Inhalers | 110 (78.5) | - | - | | |
| Non-Combination Inhalers | 20 (21.5) | - | - | | |

*Note*. Missing data may result in n's not totaling 140.

[a]1= Under $ 20,000, 2= $21,000–40,000; 3=$41,000–60,000 4= $61,000-$80,000, 5 = $81,000- 100,000, 6 = Over $100,000

[b]9= Employed full time, 8 = Working from home, full time, 7= Employed part time, 6 = Homemaker, 5 = Student, 4 = Retired, 3 = On Disability, 2 = Unemployed, 1 = Other

with Bonferroni corrections) from those completing the measures on-line. Accordingly, all subsequent analyses were collapsed across these two groups.

**Descriptive Statistics on the Outcome Measures**

Descriptive statistics for the adherence measures – MARS at Time 1 and 2 and the diary measures - are presented in Table 5. Internal consistency for the MARS was good ($\alpha = .86$ at Time 1 and $\alpha = .87$ at Time 2). The scale means of 4.21 and 4.37 respectively, were close to the highest possible score of 5, indicating that participants reported high levels of compliance. Consistent with the elevated reported compliance levels, both MARS scores were negatively skewed. Transformations failed to produce normal distributions.

Adherence was derived from the daily diaries as follows: The number of prescribed medication doses was subtracted from the absolute value of the number of doses participants reported taking. These scores were averaged across each week. Accordingly, a score of 0 would indicate perfect adherence, whereas other values indicate the degree to which patients deviated from their prescribed regimen. For ease of interpretation, these scores were multiplied by -1 so that higher scores (the maximum being 0) reflect better adherence. Notably, the distributions for diary scores at Time 1 and Time 2 were highly peaked at 0, as 58.5 and 61.2 percent of patients reporting being perfectly adherent at Time 1 and 2, respectively.

Table 5

*Descriptive Statistics for the MARS and Diary Recordings*

| | n | *M (SD)* | α | Range | | Skew | Kurtosis |
|---|---|---|---|---|---|---|---|
| | | | | Potential | Observed | | |
| MARS-T1 | 137 | 4.21 (.76) | .86 | 1-5 | 1.89-5 | -5.57 | 1.67 |
| MARS-T2 | 113 | 4.37 (.65) | .87 | 1-5 | 1.78-5 | -5.85 | 3.80 |
| Diary T1 | 121 | .22 (.73) | - | - | 0 to 3.57 | 2.39 | 7.19 |
| Diary T2 | 105 | .27 (.87) | - | - | 0 to 4 | 1.98 | 4.90 |

A repeated measures *t*-test of MARS-T1 versus MARS-T2 scores indicated that reported adherence across the sample increased from baseline to one month post-appointment, $t(110) = 2.35$, $p < .05$. This effect was driven by changes in those attending the clinic for the first time at baseline ($t(48) = 2.25$, $p < .05$); those whose baseline measure was taken at a follow-up visit did not have higher adherence scores one-month post appointment, $t(61) = 1.19$, *ns*. A comparable analysis of participants' diary scores assessed at one and four weeks post appointment indicated no difference between diary scores at one week and four weeks either in the entire sample, $t(101) =. 53$, *ns,* or in the new or returning clinic attendees ($t(45) = .69$, *ns*, and $t(55) = 1.38$, *ns,* respectively). Accordingly, diary scores were collapsed across the two time points.

Spearman correlations among the adherence measures are presented in Table 6. Diary scores were significantly, albeit weakly, correlated with the MARS scores at T1 ($r_s = .26$) and modestly correlated with the MARS scores one month post-appointment ($r_s = .35$).

**Belief Measures**

**Descriptive statistics.**

The descriptive statistics for the illness belief (IPQ-R) and views about asthma medications (BMQ) subscales are presented in Tables 7 and 8, respectively. All IPQ-R subscales were reasonably internally consistent (all α's higher than .60), except for the immunity as cause subscale (α = .44). Of the remaining IPQ-R scales, the next lowest internal consistency was for the treatment control scale (α = .63). This is not surprising, given that the treatment control subscale does not differentiate between preventer versus

Table 6

*Spearman Correlations Amongst Adherence Measures*

| Scale | 2 | 3 |
|---|---|---|
| 1. MARS T1 | .52** | .26** |
| 2. MARS T2 | - | .35** |
| 3. Diary Scores | | - |

** $p < .001$.

Table 7

*Descriptive Statistics for Beliefs about Asthma Measures*

| IPQ-R Subscale | n | *N* of items | *M (SD)* | Cronbach's α | Range | | Skew | Kurtosis |
|---|---|---|---|---|---|---|---|---|
| | | | | | Potential[a] | Observed | | |
| Identity | 76 | 14 | 4.80 (2.69) | n/a | 0 – 14[b] | 0 - 14 | -.17 | 6.94 |
| Timeline | 139 | 5 | 4.05 (.88) | .89 | 1 – 5 | 1.6 - 5 | -3.46 | .50 |
| Acute/Chronic | | | | | | | | |
| Consequences | 139 | 6 | 3.24 (.85) | .83 | 1 – 5 | 1.17 - 5 | -.09 | -.10 |
| Personal Control | 139 | 6 | 3.97 (.61) | .77 | 1 – 5 | 2.33 - 5 | -1.43 | -.56 |
| Treatment Control | 137 | 5 | 3.79 (.53) | .63 | 1 – 5 | 1.8 - 5 | -2.87 | 4.02 |
| Illness Coherence | 137 | 5 | 3.55 (.82) | .88 | 1 – 5 | 2 - 5 | -1.15 | -1.47 |
| Timeline Cyclical | 137 | 4 | 3.35 (.73) | .68 | 1 – 5 | 1.25 - 5 | -.14 | .25 |
| Emotion | 137 | 6 | 2.72 (.85) | .85 | 1 – 5 | 1 – 4.67 | .08 | -1.38 |

| IPQ-R Subscale | n | *N* of items | *M (SD)* | Cronbach's α | Range | | Skew | Kurtosis |
|---|---|---|---|---|---|---|---|---|
| | | | | | Potential[a] | Observed | | |
| Causes | | | | | | | | |
| Psychological | 137 | 6 | 2.59 (.85) | .87 | 1 – 5 | 1 – 4.33 | -.99 | -1.65 |
| Risk Factors | 137 | 6 | 2.71 (.77) | .70 | 1 – 5 | 1 – 4.5 | .30 | -.28 |
| Immunity | 137 | 3 | 3.16 (.76) | .44 | 1 – 5 | 1 - 5 | -1.21 | .96 |
| Accident/Chance | 137 | 1 | 2.16 (1.09) | n/a | 1 – 5 | 1 - 5 | 3.40 | -.68 |
| Breathing Airways | 137 | 2 | 3.46 (1.03) | .80 | 1 – 5 | 1 - 5 | -3.32 | .61 |

[a]1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree nor Disagree, 4 = Agree, 5 = Strongly Agree. [b]0 = Experiencing no symptoms to 14 = Experiencing all listed symptoms.

Table 8

*Descriptive Statistics for Beliefs about Asthma Medication Scales*

| BMQ Subscale | n | N of items | *M (SD)* | Cronbach's α | Skew | Kurtosis | Range | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | Potential | Observed |
| Necessity | 135 | 6 | *3.86 (.74)* | .87 | -2.11 | 1.83 | 1 - 5 | 1 - 5 |
| Preventer | | | | | | | | |
| Concerns | 135 | 8 | *2.70 (.66)* | .76 | -2.09 | .10 | 1 – 5 | 1.13 – 4.25 |
| Preventer | | | | | | | | |
| Necessity Rescue | 123 | 6 | *3.36 (.96)* | .90 | .38 | -1.28 | 1 – 5 | 1 – 5 |
| Concerns Rescue | 123 | 8 | *2.70 (.71)* | .79 | -.09 | -1.02 | 1 – 5 | 1.13 – 4.25 |

relief medications. In contrast, the BMQ was administered twice, once with reference to preventer and once with reference to rescue medications, and so each of the scales are understandably more internally consistent because all questions pertain to the same (and specific) class of medications. Accordingly, for the purposes of this study, the BMQ - Necessity of Medication subscale was used to gauge perceived efficacy of treatment rather than the IPQ Treatment control subscale.

With respect to distributional properties, the majority of the illness belief scales (severity, consequences, coherence, cause, timeline and emotional toll) and views of medicines scales were normally distributed. Exceptions were the IPQ-R Acute/Chronic Timeline subscale and Airway Problem Causal subscale (both negatively skewed) and the Accident/Injury Causal subscale (positively skewed). Consequently, correlations involving these scales were conducted using both parametric (Pearson) and non-parametric (Spearman) approaches.

**Intercorrelations among the belief measures.**

Pearson and Spearman correlations yielded identical results and so only Pearson correlations are presented in Table 9. Given the large number of correlations (120) and the accompanying risk of Type I error inflation, only those correlations exceeding .40 are considered indicative of meaningful associations.

Evident from the pattern of correlations, people with asthma clearly differentiate between the therapeutic and adverse effects of their medications; for rescue medication, the necessity and concern scales were only slightly correlated ($r = .28$, $p < .05$); these scales were uncorrelated for preventer medications ($r = .01$, *ns*). However, those who

Table 9

*Pearson Correlations among the Illness and Treatment Belief Subscales*

| Subscales | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Timeline - Acute/Chronic | -.00 | .28** | -.02 | -.31** | .21** | -.06 | -.00 | .10 | .02 | .11 | .02 | **.42**** | -.04 | .23* | -.10 |
| 2. Timeline - Cyclical | - | .31** | .07 | .05 | -.03 | .28** | .33** | .24** | .19* | .12 | .25* | .07 | .25* | .27* | .31** |
| 3.Consequence | | - | -.08 | -.20* | -.13 | .29** | .23** | .16 | .26** | .24** | **.58**** | **.40**** | .37** | .47** | .38** |
| 4. Control-Personal | | | - | **.51**** | .20* | .07 | .12 | .11 | -.08 | .07 | .20** | .23* | -.08 | -.01 | .01 |
| 5. Control-Treatment | | | | - | .15 | -.00 | -.01 | -.01 | -.06 | -.08 | -.16 | -.01 | -.21* | .05 | -.11 |
| 6. Coherence | | | | | - | -.16 | -.08 | -.02 | -.01 | .05 | .22* | .18* | -.25* | -.01 | -.28** |
| 7.Psychological Causes | | | | | | - | .65** | **.47**** | **.47**** | **.41**** | **.44**** | .04 | .32** | .19* | .28** |

| Subscales | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 8. Risk Factors | | | | | | | - | **.52**$^{**}$ | **.57**$^{**}$ | .37$^{**}$ | .21$^{**}$ | .05 | .24$^{**}$ | .14 | .23$^{**}$ |
| 9. Immunity | | | | | | | | - | **.44**$^{**}$ | **.51**$^{**}$ | .10 | .17 | .21$^{*}$ | .16 | .06 |
| 10. Accident | | | | | | | | | - | .27$^{**}$ | .05 | .12 | .28$^{**}$ | .21$^{*}$ | .18$^{*}$ |
| 11. Airway Problem | | | | | | | | | | - | .21$^{**}$ | .13 | .28$^{**}$ | .15 | .12 |
| 12. Emotional | | | | | | | | | | | - | .17$^{*}$ | **.45**$^{**}$ | .24$^{*}$ | **.45**$^{**}$ |
| 13. Necessity Preventer | | | | | | | | | | | | - | .01 | **.47**$^{**}$ | .03 |
| 14. Concern Preventer | | | | | | | | | | | | | - | .26$^{**}$ | **.84**$^{**}$ |
| 15. Necessity Rescue | | | | | | | | | | | | | | - | .28$^{*}$ |
| 16. Concern Rescue | | | | | | | | | | | | | | | - |

$^{**}$ $p < .001$ , $^{*}$ $p < .05$

had concerns about their preventer medications were also quite concerned about rescue medications ($r = .84$, $p < .001$). Beliefs about the efficacy of these two classes of medication appear less closely coupled ($r = .47$, $p < .001$). Interestingly, participants believed more strongly about the need for their preventer than rescue medications (3.86 versus 3.36, repeated measures, $t(119) = 6.45$, $p < .001$), though were equally concerned (2.70) about both, $t(119) = .24$, *ns.*

With respect to the association between medication belief and illness belief subscales, necessity for preventer medication was correlated with the Timeline-Acute/Chronic subscale ($r = .42$, $p <.001$), indicating that those who viewed their condition as more chronic believed that their preventer was more necessary. Not surprisingly, this association was weaker for beliefs about the need for rescue medication ($r = .23$, $p < .05$). Moreover, the consequence scale (which can be taken as an index of perceived severity) was significantly positively correlated with the perceived needs for both preventer and rescue medications ($r = .40$, $p < .001$, $r = .47$, $p < .001$, respectively) and, to a lesser degree, with concerns about taking them ($r = .37$, $p < .001$, $r = .38$, $p < .001$, respectively).

**Knowledge Data**

As noted earlier, each of the items on the knowledge scale was scored as either 3 = “correct”, 2 = “unsure”, or 1 = “incorrect”. A total score as well as subscale scores were calculated by adding up all the relevant items and dividing them by the number of items in the scale. Accordingly, higher scores indicate more knowledge in given domain.

Descriptive statistics for the knowledge questionnaire subscales are presented in Table 10. The internal consistency scores for the various subscales (which, as reported earlier, were classified as such based on expert ratings) are quite low, with none exceeding an α of .51. This is not a concern because units of knowledge reasonably could be expected to be discrete.

A repeated measures MANOVA with contrasts on the means demonstrated that, as a group, participants were most knowledgeable about their symptoms and environmental triggers and least knowledgeable about their medications, $F(4,132) = 91.14$, $p < .001$. Participants who were attending the asthma clinic for the first time when recruited for the study were no less knowledgeable in any of the content areas than those for whom it was a follow-up visit, $F(5, 130) = 1.8$, *ns*. Items, grouped by category, are presented in the order of most to least correctly answered in Appendix L.

Whereas overall knowledge, knowledge of the pathophysiology and knowledge about medication were normally distributed, the technique and environment subscales were significantly negatively skewed and the symptom subscale was highly negatively skewed and had a very peaked distribution. Notably, 66% of the sample responded correctly to all symptom scale items (i.e., obtained a mean score of 3 on this scale). Accordingly, Spearman correlations were conducted in subsequent analyses to meet assumption criteria.

Pearson and Spearman correlations amongst the knowledge subscales are presented in Table 11. The strongest correlation was between knowledge about the pathophysiology of the disease and the medications necessary to treat it ($r = .42$, $p < .001$).

Table 10

*Descriptive Statistics for Knowledge about Asthma Subscales*

| Scale | N of Items | n | *M*[a] | *SD* | Cronbach's α | Skew | Kurtosis |
|---|---|---|---|---|---|---|---|
| Pathophysiology | 9 | 137 | 2.72 | .23 | .42 | -2.95 | .47 |
| Medication | 12 | 137 | 2.44 | .28 | .51 | -.57 | -1.44 |
| Technique | 4 | 139 | 2.64 | .32 | .04 | -3.34 | .59 |
| Symptom | 4 | 139 | 2.86 | .25 | .13 | 12.37 | 20.65 |
| Environment | 6 | 139 | 2.84 | .18 | .40 | -5.44 | 2.34 |
| Total Scale | 35 | 139 | 2.65 | .16 | .64 | -2.47 | 1.27 |

[a]1 = Incorrect, 2 = Unsure, 3 = Correct.

Table 11

*Intercorrelations Among Knowledge Subscales*

| Subscale | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| 1. Pathophysiology | r = **.42**$^{**}$ | r = .05 | r = .26$^{**}$ | r = .30$^{**}$ |
| | $r_s$ = **.40**$^{**}$ | $r_s$ = .08 | $r_s$ = .27$^{**}$ | $r_s$ = .30$^{**}$ |
| 2. Medication | - | r = -.07 | r = .28$^{**}$ | r = .19$^{*}$ |
| | | $r_s$ = -.06 | $r_s$ = .31$^{**}$ | $r_s$ = .21$^{*}$ |
| 3. Technique | | - | r = .23$^{**}$ | r = .01 |
| | | | $r_s$ = .21$^{**}$ | $r_s$ = -.04 |
| 4. Environment | | | - | r = .27$^{**}$ |
| | | | | $r_s$ = .12 |
| 5. Symptoms | | | | - |

$^{**}$ $p < .01$ , $^{*}$ $p < .05$

**Correlations between Knowledge and Belief Data**

Given that this is the first study to explore the relative roles of asthma knowledge and beliefs, exploratory Pearson correlations were conducted for the normally distributed variables. Both Spearman and Pearson correlations were conducted for the non-normally distributed variables, and yielded equivalent findings. Accordingly, only Pearson correlation coefficients are reported (See Table 12). Again, given the large number of correlations (96) only those exceeding .40 were deemed meaningful. Only two such correlations met these criteria. Specifically, the belief that asthma is chronic (rather than acute) was positively associated with overall knowledge about asthma ($r = .41$, $p < .001$) and more specifically with knowledge about its pathophysiology ($r = .48$, $p < .001$).

**Correlations between Predictor Variables and Adherence Measures**

Correlations among the beliefs and knowledge subscales and the adherence outcome measures are presented in Table 13. Given that MARS and diary scores were significantly skewed, both Pearson and Spearman correlations were conducted. To control for Type I error (given 44 associations were being examined), only correlations in which either the Spearman or Pearson coefficient exceeded .25 were deemed to indicate statistically meaningful associations. Only three such associations met this criterion. Specifically, self-reported adherence at Time 2 (i.e., MARS-T2) was positively correlated with the belief that asthma is a chronic condition ($r = .26$), the belief that preventer medications are necessary ($r = .36$) and with knowledge about the pathophysiology of asthma ($r = .27$). Notably, adherence as gauged by the diary method was not correlated with any of the knowledge nor belief measures.

Table 12

*Pearson Correlations between Belief and Knowledge Subscales*

| | Knowledge Scales | | | | | |
|---|---|---|---|---|---|---|
| Belief Scale | Knowledge Total | Pathophysiology Subscale | Medication Subscale | Technique Subscale | Environment Subscale | Symptoms Subscale |
| Timeline - Acute/Chronic | **.41**$^{**}$ | **.48**$^{**}$ | .24$^{**}$ | .18$^{*}$ | .19$^{*}$ | .13 |
| Timeline - Cyclical | -.06 | .02 | -.14 | -.01 | .09 | .16 |
| Consequence | -.01 | .10 | -.10 | .06 | .05 | .10 |
| Control- Personal | .14 | .16 | .08 | .05 | .14 | .10 |
| Control- Treatment | .05 | .01 | .02 | -.03 | .11 | .04 |
| Coherence | .22$^{**}$ | .22$^{**}$ | .16 | .04 | .14 | .04 |
| Psychological Causes | -.08 | -.02 | -.21$^{*}$ | .14 | .09 | .04 |

| Belief Scale | Knowledge Total | Pathophysiology Subscale | Medication Subscale | Technique Subscale | Environment Subscale | Symptoms Subscale |
|---|---|---|---|---|---|---|
| Risk Factors | -.08 | .01 | -.14 | .01 | .06 | -.01 |
| Immunity | .10 | .14 | -.06 | .12 | .24** | .10 |
| Accident | -.10 | -.01 | -.13 | -.00 | -.01 | -.07 |
| Airway Problem | .15 | .14 | .07 | .11 | .17* | .04 |
| Emotional | -.17* | -.12 | -.18* | -.01 | -.06 | .04 |
| Necessity Preventer | .10 | .22** | -.03 | .08 | .12 | .11 |
| Concern Preventer | -.22* | -.25** | -.13 | -.05 | -.10 | -.08 |
| Necessity Rescue | -.13 | -.13 | -.15 | -.08 | -.01 | .04 |
| Concern Rescue | -.29** | -.29** | -.20* | -.01 | -.04 | -.07 |

** $p < .001$ , * $p < .05$

Table 13

*Correlations of Belief and Knowledge Scales with Adherence Measures*

| Subscale | MARST2 | | Diary Recordings | |
|---|---|---|---|---|
| | *r* | $r_s$ | *r* | $r_s$ |
| **Beliefs** | | | | |
| Identity | -.04 | -.10 | -.02 | -.06 |
| Acute/Chronic | **.27**** | **.25**** | .06 | .01 |
| Timeline- Cyclical | -.12 | -.16 | .06 | .06 |
| Consequences | .05 | -.08 | .06 | .06 |
| Personal Control | .15 | .12 | -.05 | -.06 |
| Treatment Control | -.01 | .06 | -.12 | -.11 |
| Coherence | .09 | .05 | .04 | .06 |
| Emotional | -.05 | -.10 | .14 | .13 |
| Psychological | -.18 | -.21* | -.00 | -.02 |
| Risk Factors | -.11 | -.17 | .01 | .04 |
| Immunity | -.06 | -.05 | -.04 | -.02 |
| Airways | -.07 | -.10 | .11 | .12 |
| Accident | -.11 | -.16 | -.02 | .05 |
| Preventer | **.36**** | **.33**** | .11 | .07 |
| Necessity | | | | |
| Preventer Concern | -.20* | -.21* | .00 | .03 |
| Rescue Necessity | .09 | .07 | .01 | .04 |

| | | | | |
|---|---|---|---|---|
| Rescue Concern | -.06 | -.14 | -.04 | -.04 |
| **Knowledge** | | | | |
| Pathophysiology | **.27**$^{**}$ | **.25**$^{**}$ | .11 | .12 |
| Medication | .17 | .23$^{**}$ | -.08 | -.01 |
| Technique | -.00 | -.01 | -.05 | -.08 |
| Environment | .14 | .08 | .01 | .03 |
| Symptoms | .08 | .09 | .07 | .04 |

*Note*. $r$ = Pearson correlation, $r_s$ = Spearman correlation.

$^{*}$ $p < .05$, $^{**}$ $p < .001$.

## Preference Data

Preference data were extracted though a series of steps. First, a given choice was coded as either 0 (for the presumed undesirable option for each attribute) or 1 (for the presumed positive option). See Table 14 for the coding scheme. To gauge the weight a given participant placed on each of the seven attributes, total scores (ranging from 0 = Never selected a scenario with a positive level of a given attribute to 8 = Always selected the scenario with the more positive level of a given attribute) were then computed. This calculation yielded 7 total scores for each participant. Higher scores indicated that participants had selected scenarios wherein that attribute level had appeared more often. Therefore, higher scores reflect a greater weighing of the attribute.

### Latent class cluster analysis.

Total scores were analyzed using cluster analysis techniques. All analyses were conducted using Latent Gold 4.5 latent cluster analysis (LCA). LCA segments individuals into clusters based on estimated membership probabilities (Magidson & Vermunt, 2005). How best to determine the number of appropriate classes is the subject of some debate within the cluster analysis literature. However, many look to the Bayesian Information Criterion (BIC) to determine model fit (Trivedi, Ayotte, Thorpe, Edelman, & Bosworth, 2010). BIC scores aim to balance fit with model parsimony. Thus, lower BIC scores represent models with better fit. Another valuable index of model fit is the parametric likelihood ratio tests (LRT) with bootstrapped values, which compare progressive iterations of models. Should the LRT be significant, the model with a greater number of classes is deemed a better fit to the data (Trivedi et al., 2010).

Table 14

*Coding of Attribute Levels*

| Attribute | Coded 0 | Coded 1 |
|---|---|---|
| Long Term Outcomes (10 Years) | Your airways will be **worse** in 10 years | Your airways will be the **same** in 10 years |
| Short Term Outcomes (6 Months) | You will have **more** asthma attacks over the next 6 months | You will have **less** asthma attacks over the next 6 months |
| Immediate Effects | Your medication will relieve your symptoms within **30** minutes | Your medication will relieve your symptoms within **5** minutes |
| Steroid Dose | **High** dose of steroids | **Low** dose of steroids |
| Number of Inhalers | **Two** | **One** |
| Dosing Only As Needed | Every day at **set times** and more when I need it | **Only when I need it** |
| Side Effects | There is a risk **of major/long term** side effects | There is a risk of **minor/short term** side effects |

To determine the presence of latent classes among preference choices, 1,2,3,4, and 5 class models were tested. As per the fit indices presented in Table 15, the five cluster model had the lowest BIC score and the LRT was significant and so would have been chosen on solely empirical grounds. However, on the basis of interpretability (see below), the four cluster model was deemed superior to the five cluster model.

The 4 and 5 cluster models are illustrated in Figures 2 and 3, respectively. Patterns among the mean scores of the first two clusters (i.e., long term outcomes and side effects) are virtually identical in the 4 and 5 cluster models (see Figures 4 and 5). Cluster 1 (long term outcomes) accounts for 30% of the sample in both models and Cluster 2 (side effects) accounts for approximately 20% of the sample in both models. As is evident in Figure 6, both the 4 and 5 cluster models produce a group of participants who weigh all the attributes more or less equally when making their decision (Cluster 3-equal weighting). In the four cluster model, this group accounts for approximately 30% of the sample. However, in the five cluster model, this group accounts for only 18% of the sample. This is because in the 5 cluster model, this group, hovering around the middle range of scores (i.e., between 3 – 5), is differentiated into 3 groups (refer back to Figure 3). However, given that the design was not perfectly balanced this distinction may simply be a function of methodological error. In addition, the last cluster of the 4 cluster model was no longer differentiated in the 5 cluster model. Given these issues, the 4 cluster model was deemed a better fit.

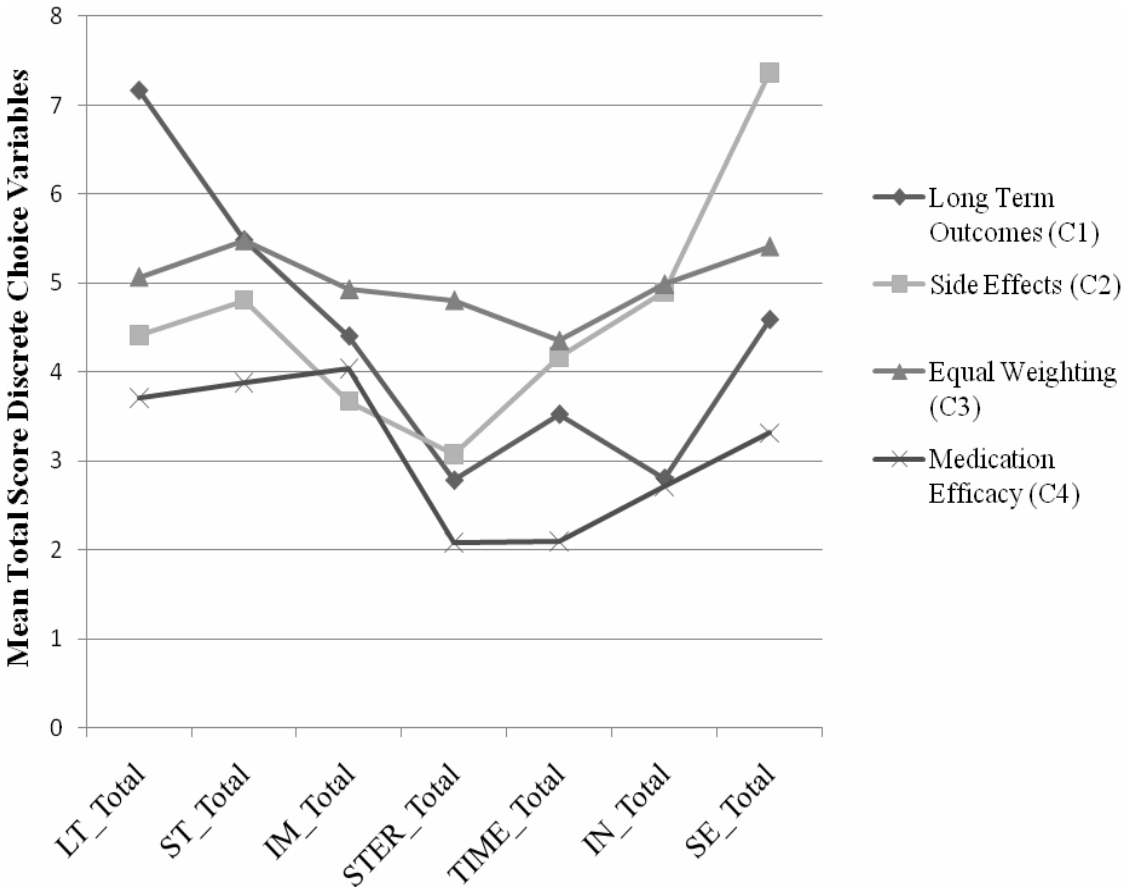
Table 15

*Model Fit Indices*

| Model | LL | BIC (LL) | Npar | $L^2$ | BIC ($L^{2)}$ | *df* | *p*-value |
|---|---|---|---|---|---|---|---|
| 1 Cluster | -1449.41 | 3089.84 | 39 | 2046.43 | 1581.14 | 1.1e-363 | 0.000 |
| 2 Cluster | -1349.75 | 2929.70 | 47 | 1847.11 | 1420.99 | 9.9e-328 | 0.005 |
| 3 Cluster | -1309.20 | 2887.78 | 55 | 1766.00 | 1379.07 | 2.8e-316 | 0.012 |
| 4 Cluster | -1287.41 | 2883.39 | 63 | 1722.43 | 1374.68 | 1.0e-312 | 0.018 |
| 5 Cluster | -1242.64 | 2833.02 | 71 | 1632.88 | 1324.31 | 1.2e-299 | 0.012 |

Figure 2

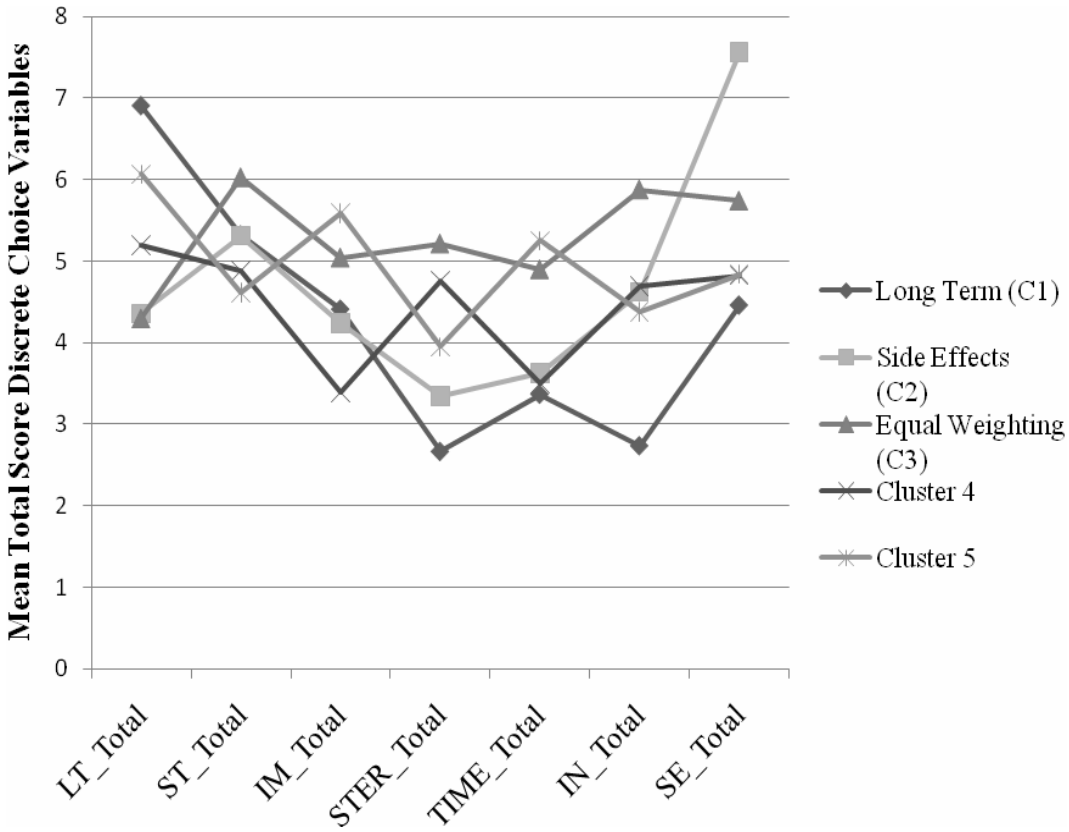
*Four Cluster Latent Class Model*




*Note.* LT = Long term total, ST = Short term total, IM = Immediate effects, STER = Steroid Dose, TIME = Time of day required to take medications, IN = Number of inhalers, SE = Side effects.

Figure 3

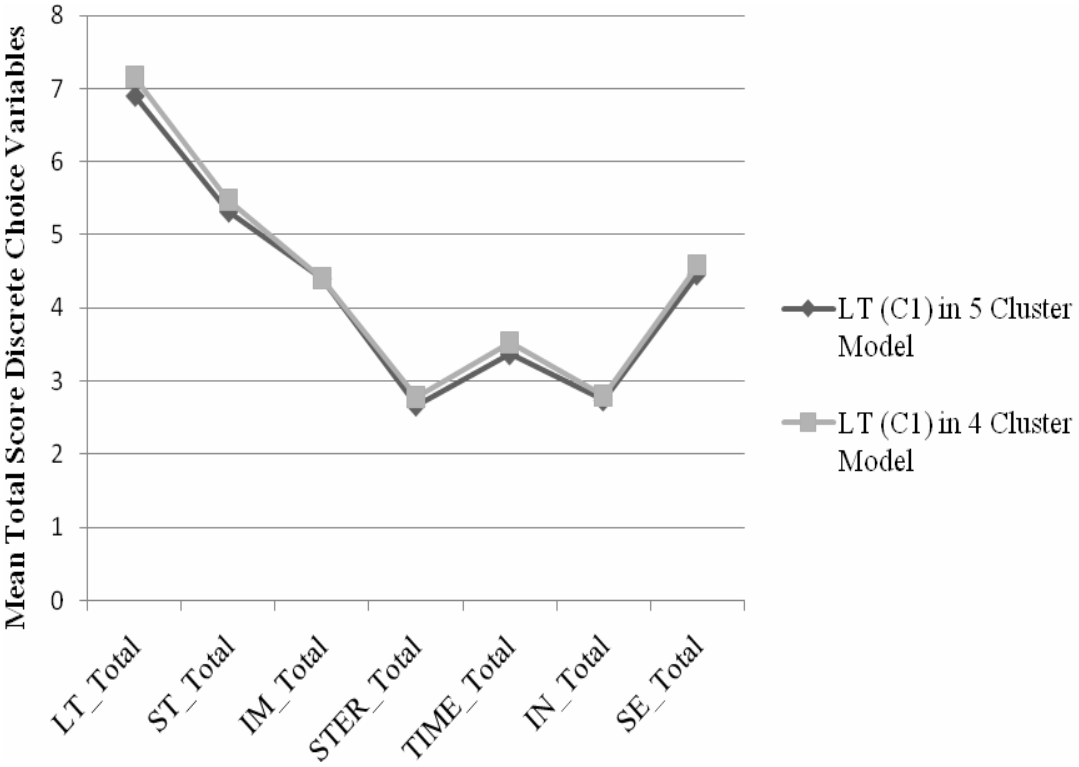
*Five Cluster Latent Class Model*




*Note.* LT = Long term total, ST = Short term total, IM = Immediate effects, STER = Steroid Dose, TIME = Time of day required to take medications, IN = Number of inhalers, SE = Side effects.

Figure 4

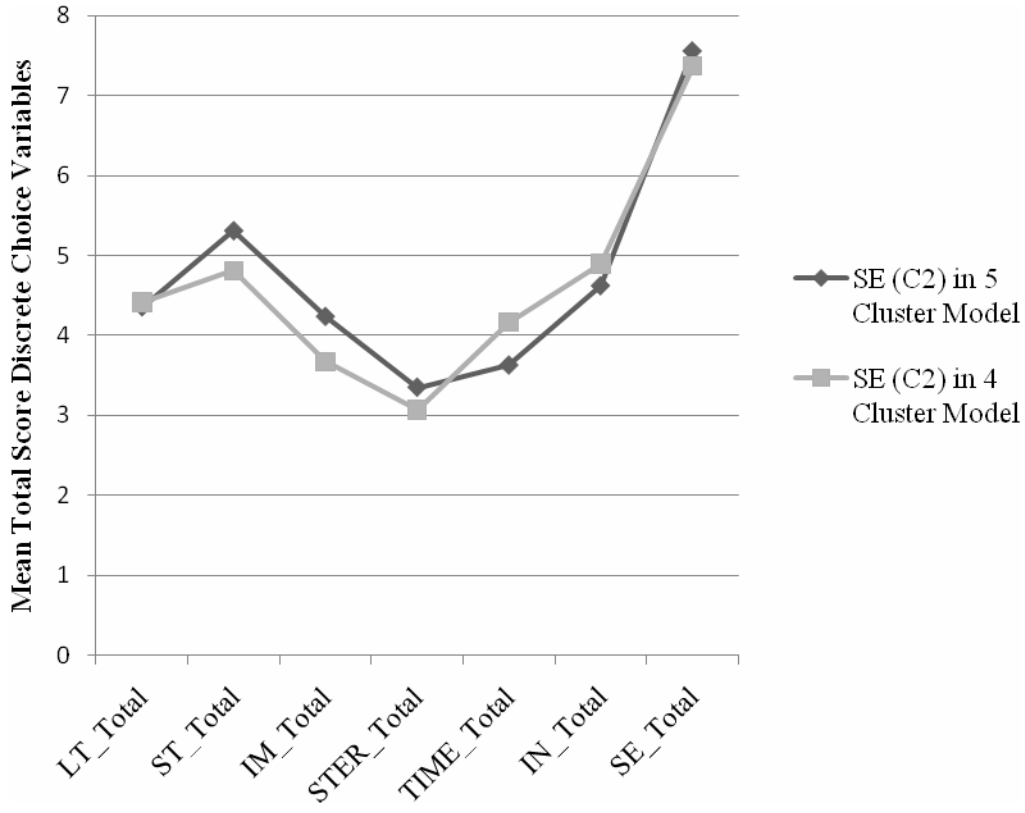
*Attribute Weights for Long Term Outcome Group in 4 and 5 Cluster Models*




*Note.* LT = Long term total, ST = Short term total, IM = Immediate effects, STER = Steroid Dose, TIME = Time of day required to take medications, IN = Number of inhalers, SE = Side effects.

Figure 5

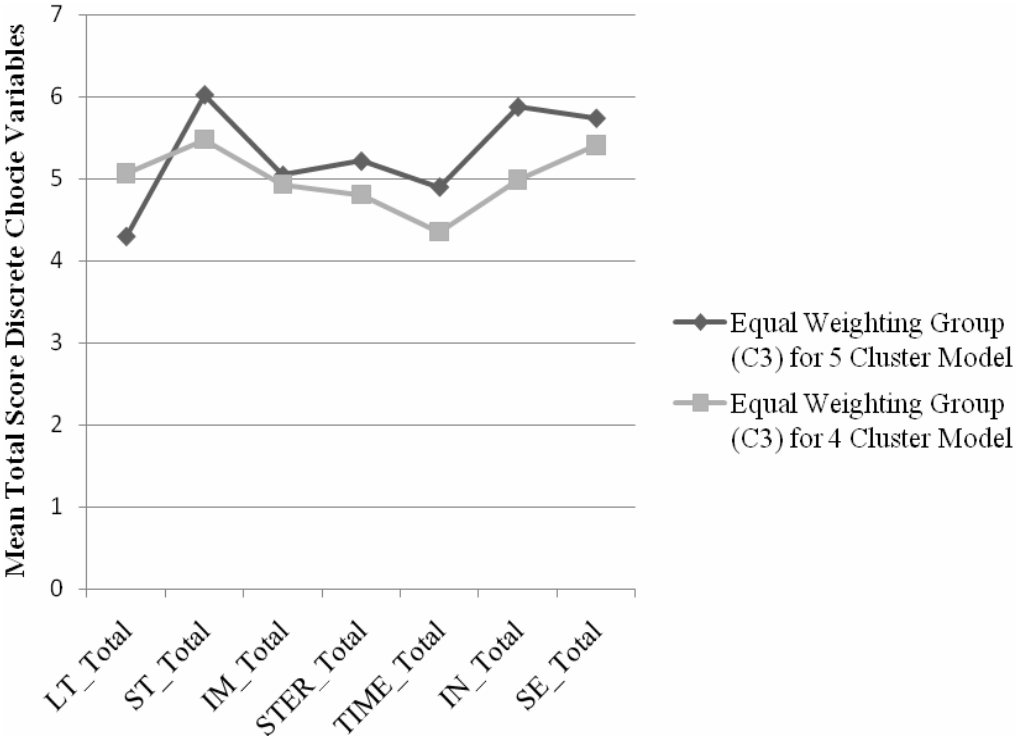
*Attribute Weights for Side Effect Group in 4 and 5 Cluster Models*




*Note.* LT = Long term total, ST = Short term total, IM = Immediate effects, STER = Steroid Dose, TIME = Time of day required to take medications, IN = Number of inhalers, SE = Side effects.

Figure 6

*Attribute Weights for Equal Weight Group in 4 and 5 Cluster Models*




*Note.* LT = Long term total, ST = Short term total, IM = Immediate effects, STER = Steroid Dose, TIME = Time of day required to take medications, IN = Number of inhalers, SE = Side effects.

Focusing then on the 4 cluster model, a numerical depiction of how the four clusters identified by the model differentially weighed attributes is presented in Table 16. The largest number of participants ($n$ = 44; 33% of the sample) fell into Cluster 1 which most valued the long term (i.e., 10 year) outcomes associated with their medications. Individuals in this cluster almost always selected scenarios in which lung function would remain the same (rather than worsen) over the next 10 years. Those in Cluster 2 ($n$ = 28; 21% of the sample) appeared to value low side effects. That is, they almost always chose scenarios describing minor and short term (rather than major and long term) side effects. Cluster 3 ($n$ = 36; 27% of the sample) respondents appeared to accord equal weight to all seven attributes. And finally, those in Cluster 4 ($n$ = 26; 19% of the sample) valued all outcomes, be they immediate, intermediate or long-term. Participants in this cluster were willing to trade off more side effects, a higher dose of steroids and a more complex treatment regimen (more inhalers, fixed dosing plus as needed versus only as needed) for better efficacy immediately, and in the short and long term treatment range.

A MANOVA revealed no significant differences in demographic characteristics (gender, age, education, employment status, and clinic visits) between the clusters, $F(21,327) = .67$, *ns.*

**Differences in beliefs and knowledge among clusters.**

Exploratory MANOVA analyses were conducted to determine whether individuals in the clusters differed with respect to their beliefs and knowledge about asthma. Box's tests were all non-significant, indicating that the matrices were equivalent despite the unequal sample sizes across groups. As such, all analyses met the assumption of homogeneity of the covariance matrices.

Table 16

*Means of Total Scores among Clusters*

| | Cluster 1: Long Term Outcome (n = 44) | Cluster 2: Side Effects (n = 28) | Cluster 3: Equal Weighting (n = 36) | Cluster 4: Medication Efficacy (n = 26) |
|---|---|---|---|---|
| 10 Year Effects | 7.16 | 4.41 | 5.07 | 3.71 |
| 6 Months Effects | 5.48 | 4.81 | 5.48 | 3.89 |
| Immediate Effects | 4.40 | 3.67 | 4.93 | 4.04 |
| Steroid Dose | 2.78 | 3.07 | 4.80 | 2.08 |
| Medications As Needed | 3.52 | 4.16 | 4.35 | 2.10 |
| Number of Inhalers | 2.80 | 4.90 | 4.98 | 2.74 |
| Side Effects | 4.49 | 7.40 | 5.41 | 3.31 |

*Note.* Column totals are not all equal because the design is orthogonal, but not perfectly balanced.

As per Roy's largest root, there was a significant effect of clusters on beliefs, $F(14,114) = 2.17$, $p < .05$, partial $\varepsilon^2 = .21$. Separate univariate ANOVAs (Table 17) on the outcome variables revealed that the groups differed with respect to their beliefs about problems with their airways being the cause of their condition. Follow-up contrasts with LSD corrections indicated that participants who preferred long term outcomes were more likely to believe that "airway problems" were the cause of their condition than both those who weighed all treatment elements equally and those valuing treatment efficacy (Table 18).

A second MANOVA also was conducted to assess differences in asthma knowledge across clusters. Again, as per Roy's largest root, there was a significant multivariate effect of clusters on knowledge, $F(5,125) = 2.45$, $p < .05$, partial $\varepsilon^2 = .09$. Separate univariate ANOVAs revealed that the groups differed with respect to knowledge about asthma pathophysiology as well as asthma medications (see Table 19). Follow-up contrasts (LSD correction; Table 20) for asthma pathophysiology indicated that those weighing all attributes equally (Cluster 3) were less knowledgeable about asthma pathophysiology and asthma medications than were those who privileged long term outcomes (Cluster 1) and those who valued medication efficacy above the negative elements of medications (Cluster 4). Moreover, those most concerned about side effects (Cluster 2) were less knowledgeable about asthma pathophysiology than those who most valued short, intermediate or long- term outcomes (Cluster 4).

Table 17

*Summary of Univariate ANOVA Statistics of Beliefs by Cluster*

| | Sum of Squares | df | Mean Square | F | Partial eta$^2$ |
|---|---|---|---|---|---|
| Timeline- Acute/Chronic | .11 | 3 | .04 | .05 | .00 |
| Consequences | .15 | 3 | .05 | .07 | .00 |
| Personal Control | .29 | 3 | .10 | .17 | .00 |
| Treatment Control | .44 | 3 | .15 | .53 | .01 |
| Coherence | 3.19 | 3 | 1.06 | 1.60 | .04 |
| Timeline- Cyclical | .50 | 3 | .17 | .31 | .01 |
| Emotional | .29 | 3 | .10 | .14 | .00 |
| Psychological Cause | 5.23 | 3 | 1.75 | 2.55 | .06 |
| Risk Factors | .57 | 3 | .19 | .31 | .01 |
| Immunity | .95 | 3 | .32 | .54 | .01 |
| Problem with Airways | 8.99 | 3 | 2.99 | **3.03**$^*$ | .07 |

| | Sum of Squares | df | Mean Square | F | Partial eta$^2$ |
|---|---|---|---|---|---|
| Accident/Injury | 3.92 | 3 | 1.31 | 1.09 | .03 |
| Necessity of Preventer | 1.26 | 3 | .42 | .76 | .02 |
| Concern for Preventer | 2.27 | 3 | .76 | 1.8 | .04 |

$^{*}p < .05$.

Table 18

*Estimated Marginal Means for Beliefs about Airway Problems as a Cause of Asthma by Cluster Group*

| Cluster Group | *M* | *SE* |
|---|---|---|
| Long term effects (C1) | 3.77 | .17 |
| Side Effects (C2) | 3.39 | .19 |
| Equal Weighting (C3) | 3.16 | .15 |
| Medication Efficacy (C4) | 3.73 | .20 |

Table 19

*Summary of Univariate ANOVA Statistics for Difference of Knowledge by Clusters*

| | Sum of Squares | df | Mean Square | F | Partial $eta^2$ |
|---|---|---|---|---|---|
| Pathophysiology | .40 | 3 | .13 | 2.70* | .06 |
| Medications | .61 | 3 | .20 | 2.79* | .06 |
| Technique | .20 | 3 | .07 | .65 | .02 |
| Symptoms | .20 | 3 | .07 | 1.04 | .02 |
| Environmental Triggers | .15 | 3 | .05 | 1.41 | .03 |

*$p < .05$.

Table 20

*Estimated Marginal Means for Knowledge of Pathophysiology and Medication by Cluster*

| | Pathophysiology | | Medication | |
|---|---|---|---|---|
| | *M* | *SE* | *M* | *SE* |
| Long term effects (C1) | 24.72 | .31 | 29.95 | .49 |
| Side Effects (C2) | 24.18 | .38 | 28.68 | .61 |
| Equal Weighting (C3) | 23.92 | .33 | 28.17 | .54 |
| Medication Efficacy (C4) | 25.29 | .41 | 30.04 | .66 |

**Testing Study Hypotheses**

*Hypothesis 1*: *Knowledge about the pathophysiology of asthma will predict treatment adherence.*

As per a linear regression analysis, knowledge of asthma pathophysiology predicted MARS scores one month post-appointment, accounting for 6 percent of the explained variance, $R^2 = .06$, $F(3,106) = 2.15$, $p < .05$. This finding remained unchanged when the demographic variables which correlated with pathophysiology knowledge (i.e., education level and number of family doctor visits in the past year) were entered at step 1 (Table 21).

As expected, given the non-significant correlations between any of the knowledge subscales and reported diary adherence, knowledge of the pathophysiology of asthma did not predict diary reported medication use, $R^2 = .01$, $F(1, 120) = 1.47$, *ns.*

*Hypothesis 2: Beliefs about the chronicity of the disease, amount of control, severity of symptoms, sense of coherence and necessity of preventer medications will predict increased treatment adherence.*

As noted earlier, of the illness belief variables, only the Acute/Chronic Timeline scale was appreciably correlated with adherence scores. Because the hypotheses were related to the unique contribution of each belief, rather than their contribution as a belief set, only the Acute/Chronic Timeline variable was used as predictor in the regression analysis. With respect to beliefs about medication, both beliefs about the need for and concern

Table 21

*Summary of Multiple Regression Analysis for Patient Knowledge as a Predictor of Reported Adherence (MARS-T2) to Asthma Preventer Medication*

| | Model | |
|---|---|---|
| Variable | 1 β | 2 β |
| Demographics | | |
| Level of Education | -.01 | -.00 |
| Visits to Family MD in past year for breathing symptom | .07 | -.04 |
| Pathophysiology Knowledge | | **.24*** |
| $R^2$ | .01 | .06 |
| $\Delta R^2$ | - | .05 |
| $F$ | .29 | 2.15 |
| $\Delta F$ | - | 5.86* |

*$p < .05$.

about preventer medications were correlated with adherence and were thus retained in the regression analysis (Table 22), which indicated that the hypothesized beliefs predicted MARS scores at one month post-appointment, accounting for approximately 20 % of the explained variance, $R^2 = .21$, $F(7,96) = 3.63$, $p < .01$. The amount of variance accounted for was unchanged when the demographic variables which correlated with the belief scales (i.e., participants' education level, current job status, age, and number of ER and clinic visits) were entered at step 1 (Table 22).

Surprisingly, when entered simultaneously, treatment beliefs (i.e., the belief in the necessity of taking a preventer medication and less of a concern about the effects of the medication) but not illness beliefs (about timeline) significantly predicted adherence. To test the possibility that this arose because the predictive power of believing one has a chronic illness is mediated by beliefs about the necessity of preventer medications (the variables are correlated $r = .42$), a Sobel test (Preacher and Leonardelli, 2001) was performed to test whether treatment necessity mediated the relationship between chronicity beliefs and adherence (Baron and Kenny, 1986). The Sobel test indicated that necessity did partially mediate ($t = 2.70$, $p < .001$) the relationship between chronicity beliefs and adherence. And, parenthetically, the opposite did not hold; that is, chronicity beliefs did not mediate the relationship between treatment necessity and adherence.

A regression including all the hypothesized beliefs measures explained virtually none of the variance in diary-reported adherence, $R^2 = .01$, $F(3,116) = .51$, *ns*.

Table 22

*Summary of Multiple Regression Analysis for Patient Illness and Treatment Beliefs as Predictors of Reported Adherence (MARS-T2) to Asthma Preventer Medication*

| | Model | |
|---|---|---|
| Variables | 1 β | 2 β |
| Demographics | | |
| Age | .16 | .16 |
| Education | .10 | .06 |
| Visits to Family MD in past year for breathing symptoms | -.04 | -.03 |
| Visits to ER in past year for breathing symptoms | -.01 | .02 |
| Beliefs | | |
| Acute/Chronic Timeline | | .04 |
| Preventer Necessity | | **.34**$^{***}$ |
| Preventer Concern | | **-.23**$^{*}$ |
| $R^2$ | .04 | .21 |
| $\Delta R^2$ | - | .17 |
| $F$ | 1.01 | **3.63**$^{**}$ |
| $\Delta F$ | - | **6.88**$^{***}$ |

$^{*}p < .05.$ $^{**}p < .01.$ $^{***}p < .001.$

*Hypothesis 3: Patient preferences will predict adherence. In particular, patients who value long term outcomes will be more adherent than those who do not value long term outcomes.*

Participants were assigned to a cluster (1 - 4) based on their proximity to a cluster pattern. Categorical membership was dummy coded for the purpose of the regression analysis. The long term group was used as the constant comparator and was therefore assigned all zeros. As such, univariate contrasts compared each group against the long term group.

As per a regression analysis, preferences (as defined by cluster membership) predicted MARS scores at one month post appointment, accounting for 13.4 percent of the variance in adherence scores, $R^2 = .13$, $F(3,105) = 5.43$, $p < .01$ (Table 23). Beta values indicated a significant difference between participants who valued long term outcomes and those who weighed all attributes equally such that those who valued long term outcomes were more adherent to their preventer medication. Participants who valued long term outcomes were not more adherent than those who consistently preferred scenarios with minor medication side effects nor those who valued the efficacy of treatment over side effects with respect to adherence.

A regression including group classification explained virtually none of the variance in diary-reported adherence, $R^2 = .00$, $F(3, 116) = .12$, *ns.*

Table 23

*Summary of Regression Analysis for Patient Preferences as a Predictor of Reported Adherence (MARS-T2) to Asthma Preventer Medication*

| Variable | β |
|---|---|
| Equal Weighting – Long Term | **-.40**$^{***}$ |
| Side Effects – Long Term | -.04 |
| Efficacy – Long Term | -.16 |
| $R^2$ | .13 |
| $F$ | 5.42** |

$^{***}p < .001$. $^{**}p < .01$.

*Hypothesis 4: Patients' preferences for elements of their medication will predict adherence above and beyond that predicted by knowledge of their disease and beliefs about the disease and its treatment.*

A hierarchical multiple linear regression revealed that preferences for long term outcomes accounted for an additional 10% of the variance in adherence scores on the MARS at one month follow-up, after demographic variables were included in step one (i.e., age, income, and education), clinical factors included in step two (i.e., number of family doctor and emergency room visits for respiratory related problems in the past year, and number of asthma clinic visits), knowledge of pathophysiology in step 3, and beliefs in step 4 (Table 24). The full model explained 39% of the variance in reported adherence. Moreover, a reverse analysis in which preferences were entered in step 1 and beliefs and knowledge in step 2 confirmed that preferences accounted for a unique portion of explained variance (Appendix M).

An examination of the standardized beta coefficients revealed that, when the knowledge and belief variables were entered simultaneously, only the belief that medication is necessary predicted adherence (partial correlation = .42); knowledge of asthma pathophysiology was no longer predictive. To determine whether the drop in the predictive power of knowledge of pathophysiology was due to its being mediated by the belief that preventers are necessary, a Sobel test was performed. It indicated that the perceived necessity of preventer medication did, indeed, partially mediate, ($t = 2.16$, $p < .05$) the relationship between pathophysiology and adherence.

Table 24

*Summary of Hierarchical Regression Analyses for Patient Knowledge, Beliefs and Preferences as Predictors of Reported Adherence (MARS-T2) to Asthma Preventer Medication*

| | Model | | | | |
|---|---|---|---|---|---|
| Variable | 1 β | 2 β | 3 β | 4 β | 5 β |
| Demographics | | | | | |
| Income | .04 | .06 | .03 | .07 | .07 |
| Education | .14 | .12 | .05 | .05 | .04 |
| Age | .13 | .09 | .09 | .07 | .07 |
| Clinical Factors | | | | | |
| Visits to Family MD in past year for breathing symptom | | .00 | -.02 | .03 | .00 |
| Visits to ER in past year for breathing symptoms | | .01 | .04 | .05 | .09 |
| Visits to Asthma Clinic | | .12 | .13 | .07 | .11 |
| Pathophysiology | | | .26* | .17 | .24 |
| Knowledge | | | | | |
| Beliefs | | | | | |
| Timeline- Acute/Chronic | | | | -.01 | -.05 |
| Necessity of Medication | | | | **.42***** | **.37***** |
| Concern of Medication | | | | -.15 | -.10 |

| | Model | | | | |
|---|---|---|---|---|---|
| Variable | 1 β | 2 β | 3 β | 4 β | 5 β |
| Preferences | | | | | |
| Equal Weighting -Long Term | | | | | **-.30**$^{**}$ |
| Side Effects – Long Term | | | | | .06 |
| Efficacy – Long Term | | | | | -.18 |
| $R^2$ | .05 | .06 | .12 | .30 | .39 |
| $\Delta R^2$ | - | .01 | .06 | .18 | .10 |
| $F$ | 1.41 | .86 | 1.51 | 3.25$^{**}$ | 3.86$^{***}$ |
| $\Delta F$ | - | .35 | 5.16$^{*}$ | 6.55$^{***}$ | 3.90$^{**}$ |

$^{*}$ $p < .05$. $^{**}$ $p < .01$. $^{***}$ $p < .001$.

## Supplementary Analyses

Although the following analyses do not address this study's a priori hypotheses, they were nonetheless pursued to explore the added value of the novel DCE methodology and to examine the predictive power of psychosocial variables shown to predict adherence in other domains.

### Clustering versus rating scales.

To determine whether the discrete choice and rating tasks were measuring similar phenomena, Pearson correlations were conducted between the rating items and their corresponding discrete choice item total score (Table 25). Notably, only long term side effects correlated with its matched DCE variable. Although significant, the correlation was small ($r = .28$, $p < .001$). It appears, therefore, that people's overt ratings of what is important to them differ from what they are willing to give up in a trade-off situation.

A Principal Axis Factor Analysis (Oblimin rotation) of the 9 rating items corresponding to the discrete choice options suggested three factors, which explained 70.58% of the total variance. Table 26 illustrates the factor pattern matrix. For an item to be considered part of a factor, it had to load: (1) .50 or higher on the primary factor and, (2) .40 or lower on all the remaining factors. The factors were labeled: (1) Complexity of treatment (Eigen value = 3.13; percent variance = 34.78; items: number of inhalers, taking an inhaler every day, taking an inhaler only when I need it; $\alpha = .74$), (2) Efficacy of treatment (Eigen value = 1.77; percent variance = 19.69; items: relieves symptoms in minutes, keeps asthma from getting worse in 10 years, and reduces attacks over the next 6 months; $\alpha = .81$), (3) Side effects (Eigen value = 1.45; percent variance = 16.11;

Table 25

*Correlations between Rating Item and Corresponding Discrete Choice Attribute*

| Rating Item | DCE Attribute | *r* |
|---|---|---|
| 1. Keeps asthma from getting worse in 10 years | Long Term Outcome | .14 |
| 2. Number of inhalers | Number of Inhalers | -.04 |
| 3. Taking an inhaler every day | Frequency of Dose | -.04 |
| 4. Taking an inhaler only when I need it | Frequency of Dose | .10 |
| 5. Short term side effects | Side Effects | .04 |
| 6. Long term side effects | Side Effects | **.28**** |
| 7. Risk of Addiction | Steroid Dose | .15 |
| 8. Relieves Symptoms in Minutes | Immediate Effects | -.06 |
| 9. A decrease in asthma attacks over the next 6 months | Short Term Outcome | .06 |

** $p < .001$.

Table 26

*Pattern Matrix of Rating Scale Items*

| Item | Component | | |
|---|---|---|---|
| | 1 | 2 | 3 |
| Number of inhalers | **.73** | -.11 | .06 |
| Taking an inhaler every day | **.87** | .03 | -.37 |
| Taking an inhaler only when I need it | **.50** | -.05 | .30 |
| Short term side effects | .29 | .06 | **.60** |
| Long term side effects | -.14 | -.11 | **.82** |
| Risk of addiction | .01 | .03 | **.61** |
| Relieves symptoms within minutes | -.05 | **-.53** | .13 |
| Keeps asthma from getting worse in 10 years | .20 | **-.92** | .06 |
| Reduces attacks over next 6 months | .11 | **-.86** | -.11 |

items: short term side effects, long term side effects, risk of addiction; α = .71). Notably, long term outcome did not emerge as its own factor.

Only the efficacy of treatment factor (which includes the long term outcome item) correlated with the MARS-T2 scores ($r$ = .21, p< .05). However, when a linear regression analysis was performed to examine whether the rating-based preference factor scores predicted adherence on the MARS at one month follow-up, none of the factors significantly predict asthma adherence scores, $R^2$ = .06, $F(3, 109) = 3.4$, *ns*.

Cost, which was not assessed through the discrete choice scenarios (nor correlated with any of the discrete choice attribute total scores), was not significantly correlated with MARS scores.

**Other psychological factors as predictors of adherence.**

Previous studies have demonstrated that patients' sense of enablement (Haugney, Cotton, Rosen, Morrison, & Price, 2007) and satisfaction (Jackson et al., 2004) following a clinical encounter influence adherence. In addition, given that asthma (or asthma symptoms) has also been associated with increased prevalence of anxiety and panic-fear (Jessop, Rutter, Sharma, & Albery, 2004), and that negative affect has been associated with non-adherence (Lehrer, Feldman, Giardino, Song & Schmaling, 2002), exploratory correlations were conducted to see if these factors, if included, would improve the predictive power of the regression analysis. None of the factors were correlated with MARS or Diary scores, and as such, it was deemed unnecessary to add them to the regression analyses.

**Rescue medication use.**

Although this study was designed to explore the effects of knowledge, beliefs and preferences on preventer medication adherence, it is also interesting to note any associations with rescue medication use. Rescue medication use was significantly correlated only with the belief in the necessity of taking one's rescue inhaler ($r = .27$, $p < .001$, $r_s = .30$, $p < .001$) and the number of asthma symptoms experienced ($r_{identity} = .27$, $p < .05$, $r_s = .26$). Individuals in different preference clusters did not differ with respect to the frequency of rescue inhaler use, $F(68,131) = 1.07$, *ns*.

# Chapter V: Discussion

The main goal of this study was to explore the additive effects of knowledge, beliefs and preferences on preventer medication adherence in a sample of patients with asthma. Specifically, it was hypothesized that knowledge of asthma pathophysiology as well as beliefs about the consequences, chronicity, and controllability of asthma and necessity for preventer medications would be preconditions of adherence, but that preferences for long term improvements would further predict reported adherence. These predictions were borne out by the primary study findings, which are reviewed and discussed in the following sections.

## Main Findings Pertaining to MARS Reported Adherence

As expected, the study findings support the assertion that knowledge, beliefs and values pertaining to the understanding and valuing of *long term*, rather than *immediate* outcomes predicts preventer medication adherence. Specifically, when examined on their own, knowledge of asthma pathophysiology (i.e., recognizing that asthma is a tonic inflammatory condition of the lungs), perceiving the need for preventer medications (i.e., understanding that they stymie progression of the disease) and preferring long term outcomes over short term symptom alleviation, each significantly positively predicted reported adherence. When assessed together, preference for long-term improvement in asthma accounted for 10% of the variance in adherence beyond that explained by knowledge and beliefs alone. As a group, the three classes of variables accounted for 33% of the variance in adherence beyond that accounted for by demographic and clinical factors. The implications of these findings are each discussed in detail below.

**Knowledge of asthma pathophysiology is important but not sufficient.**

This was the first study to explore the extent to which specific domains of asthma knowledge predict adherence. As hypothesized, knowledge about the pathophysiology of and functional changes associated with asthma was the only knowledge domain to correlate with reported adherence ($r$ = .27). However, when entered along with treatment beliefs in a regression predicting adherence, the predictive power of pathophysiology knowledge was lost. This suggests that knowledge of pathophysiology is important only in so far as it leads one to believe that preventer medication is necessary to treat the condition. These findings are considered in greater detail below.

***Knowledge of asthma pathophysiology is the only knowledge domain to predict adherence.***

That pathophysiology was the only knowledge domain to predict adherence suggests that, in order to adhere, patients need more than simply to know *what* to do - they must understand *wh*y they are being asked to do it. The National Asthma Education Prevention Program (Bethesda, 1997) recommends that standard content areas, including inhaler technique, environmental triggers, roles of medications and self-monitoring approaches, all be included in all programs. Yet, as per these study findings, if one wants to increase the likelihood of adherence to preventer medication, it may be most efficient/cost-effective to ensure that patients understand the tonic pathophysiology of asthma and how it is targeted by corticosteroids.

Research in other domains has similarly demonstrated that, when given a rationale or explanation for a prescribed behaviour, people are more likely to comply. For example, Taylor and Bower (2004) found that undergraduates were far more likely to

wear protective gloves before applying a liquid plant fertilizer when given the following instructions: "*Gloves are recommended during application to prevent possible skin irritation and/or skin staining*" (65% compliance) than when simply told the following "*Gloves are recommended during application*" (23% compliance).

Moreover, in a series of studies on decision making heuristics and errors, Tversky and Kahneman (1983) demonstrated that the more specific a link could be made between a cause and outcome, the more easily it could be elaborated upon and perceived as likely. This may be especially important for health behaviours, wherein the consequences of perceiving an outcome to be less likely than it is really prove dangerous. This danger is compounded by people's general tendency to be optimistically biased with regard to their health (Hahn & Reiner, 1998; Renner, Knoll, & Schwarzer, 2000; Weinstein, 1980). So, anything that can counter the forces that push people away from taking medication for long-term conditions (i.e., helping them understand *why* the medication is important) should be part of the clinical armamentarium.

To re-iterate, the results of this study suggest that ensuring patients understand "why" asthma medications are necessary (i.e., the physiology of asthma and their functional impact) will promote adherence. This finding has health policy implications in that it suggests that interventions targeting adherence should focus on providing patients with the information they need to understand the mechanisms of their condition. Thus, in the interest of improving adherence, practitioners arguably should routinely include an assessment of patients' knowledge of asthma pathophysiology.

To date, however, there has been no clinical tool that adequately assesses patients' knowledge of their asthma. That is, current measures of asthma knowledge tend to tap

patients' knowledge of medications (e.g., Kritikos, Krass, Chan, & Bosnic-Anticevich, 2005) or have focused on symptoms, the stigma associated with asthma and perceptions of quality of life (e.g., Grant et al., 1999). Of those measures that assess pathophysiology, the focus is on the physiology of asthma attacks (acute bronchoconstriction) rather than the underlying chronic inflammation. For example, Allen and Jones (1998) asked participants in an asthma intervention program whether statements such as "*During an asthma attack, more mucus is produced in the airtubes"* (T) and "*During an asthma attack the airtubes collapse*" (T) were true or false. These items, however, only tap knowledge of the physiology of acute airway constriction that give rise to asthma symptoms, but not knowledge of the underlying chronic inflammatory mechanisms which are treated by preventer medication. Based on the current study's findings, it could be argued that items such as "*People with asthma can have swollen and inflamed airways even when they feel well*" (T), "*Asthma can be cured*" (F), "*When someone's asthma attack is over it means that the asthma has gone away"* (F), "*Asthma is a disease that does not last for a long time"*(F) and *"It is possible for someone's asthma to be worse without them noticing a change in their breathing"* (T*)* also should be included in these measures.

Notably, Schaffer and Yarandi (2007) included two similar items ("*People with asthma have swollen and inflamed airways even when they feel normal*" and "*Asthma can be completely cured)* in their instrument. Similarly, in a survey designed for parents of children with asthma, Ho et al. (2003) included "*Asthma is due to inflammation in the lungs*". However, one or two items are not enough to adequately assess patients' knowledge in this domain. Our scale, which included nine items targeting participants'

understanding of asthma pathophysiology, provided a more comprehensive measure of patients' knowledge in this domain.

***Beliefs about the necessity of a medication mediate the effect of pathophysiology on adherence.***

Although knowledge of pathophysiology predicts adherence, it is erroneous to assume that this knowledge, in and of itself, directly leads to adherence. A meditational analysis revealed that knowledge of asthma pathophysiology leads to adherence, in part, because it enables people to see why they should take their preventer medication; individuals must *know why* they need their medications in order to *believe* in their necessity. In fact, the variable most strongly associated with reported medication adherence was the perceived need for medication ($r$ = .36), which accounted for an additional 18% of the variance in adherence reports beyond that accounted for by participant demographics and asthma knowledge. The strength of the association between treatment beliefs and adherence is similar to that observed by Horne and Weinman (2002).

These findings are also consistent with those of others. For example, McHorney and Gadkari (2010) found that, across various conditions, patients' perceived lack of medication need (as gauged by a self-report survey) was an important factor for medication non-fulfillment rates, stronger than that of medication knowledge. Knowledge also has been shown to indirectly affect adherence through behavioural skills (Amico, Toro-Alfonso, & Fisher, 2005), personal motivation (Martin, Haskard-Zolnierek, & Dimatteo, 2010) as well as health beliefs (McHorney, 2009).

In the case of this study, one reason the effect of knowledge of pathophysiology was partly accounted for by beliefs about the need for preventer medication may be because the latter taps not only the *why* (because asthma is the result of a problem in the airways), but also the *how* (medications keep the airways from getting worse). Pathophysiology knowledge and perceived need for preventer medication were modestly correlated ($r$ = .22), suggesting that, although beliefs and knowledge are distinct, patients must understand that asthma persists even when they are not experiencing symptoms if they are to believe that the medications will help in this regard. It is thus not surprising that beliefs about the necessity of medications and beliefs about the chronic nature of asthma were moderately correlated ($r$ = .42), and that pathophysiology knowledge also moderately correlated with the belief that asthma is a chronic condition ($r$ = .48).

**Beliefs about an illness are not as strong a predictor as beliefs about its treatments.**

Contrary to prediction, the illness belief subscales did not predict reported adherence when considered in conjunction with treatment beliefs. Among other health populations, treatment beliefs also have proven to be stronger predictors of adherence than illness beliefs (Leventhal et al., 2008; McHorney & Spain, 2011). For example, in a sample of 180 stroke survivors, O'Carroll et al. (2011) observed that concerns about medications and low perceived medication benefits were the two primary predictors of poor medication adherence, whereas illness beliefs were not predictive. Similarly, in a path analysis of the effect of beliefs on reported adherence, Horne and Weinman (2002) found that necessity beliefs largely mediated the effect of illness perceptions (with the exception of consequences beliefs) on reported preventer medication adherence. These

findings were essentially replicated in this study by the finding that the association between the belief that asthma is a chronic condition and adherence to preventer medication was partly mediated by the belief that preventer medications are necessary. Why, then, might treatment beliefs better predict adherence than illness beliefs?

McHorney (2009) recently proposed a proximal-distal continuum of drivers of adherence. Adapted from Brenner's proximal-distal continuum (Brenner, Curbow, & Legro, 1995), she argues that the strength of the association between a belief and adherence is a function of the beliefs' proximity to patient decision making about whether or not to take a medication. Proximity of a belief or construct is based on how specific it is to the decision. Accordingly, McHorney hypothesized that treatment beliefs would be most proximal to the decision to not purchase a newly prescribed medication (medication non-fulfillment) or to discontinue medication use without consulting a health care provider (medication non-persistence). On the basis of bivariate and multivariate analyses of treatment beliefs, illness beliefs, and demographic factors, she found that only the perceived need for and concern about medication (i.e., treatment beliefs) differentiated adherers from non-fulfillers and non-persisters. Demographic and psychosocial factors (the most distal in McHorney's model), were only weakly associated with non-adherence, a finding which has been supported by other research (i.e., Dimatteo, 2004).

This study fails to replicate Horne and Weinman's (2002) finding that beliefs about the consequences of asthma predicts adherence to preventer medication. It should be noted, however, that the direction of their finding was counter-intuitively negative; that is, the worse impact people believed asthma to have on their lives, the less (rather

than more) likely they were to adhere. However, given that Horne and Weinman's (2002) study was cross-sectional, the finding might be explained by non-adherence leading to a worsening of asthma and thereby augmenting its adverse impact. With reference to the current study's findings, one might propose that, rather than perceived consequence exerting its effect on adherence directly, it acted through the perceived need for preventer medication, as these variables were positively correlated ($r$ =.40). However, because beliefs about consequences were not significantly correlated with adherence ($r$ = .05), there was no effect to be tested for mediation.

Notably, the only illness belief subscale to correlate with adherence in this study was the acute/chronic timeline scale ($r$ = .27), and its effect was, indeed, partially mediated by the perceived need for preventer medications. The acute/chronic timeline subscale taps beliefs about the long-lasting nature of one's condition, which, like understanding asthma pathophysiology and believing in the necessity of preventer treatment, entails an appreciation for long-term outcomes. Beliefs about the cyclical nature of the symptoms were not correlated with participants' beliefs about the chronicity of asthma. This suggests that participants differentiated between the fluctuating (or not) nature of asthma symptoms and the chronicity of its underlying pathophysiology. Appreciating the long-lasting nature of asthma and not the variability in symptoms predicted adherence. Along these lines, Schiaffino and Cea (1995) found that the ability to separate beliefs about symptoms and those about a disease predicts outcome in chronic pain. That is, they observed that when patients with chronic pain are able to make the distinction between their symptoms and their underlying disease, they came to recognize

that symptom improvement is not predicated on finding a cure for their disease and, consequently, their symptoms seem more manageable.

**Preferences predict adherence above and beyond knowledge and beliefs.**

Previous research already has shown that people with asthma have strong preferences regarding treatment. For example, McKenzie and colleagues (2001) demonstrated that, as a group, patients see cough as the most important symptom to target and reduce. Moreover, McTaggart-Cowen et al. (2008) as well as Haugney et al. (2007) found that patients are willing to trade symptom free days for a less complex treatment plan. This was the first study, however, to identify clusters of asthma patients based on treatment preferences and to subsequently use the clusters to predict adherence behaviour. Four groups, those privileging (1) long term benefits, (2) medication side effects, (3) a trade-off between side effects and efficacy and (4) all attributes equally, emerged. As predicted, a regression analysis indicated that preferences for long term outcome predicted improved adherence scores, accounting for an additional 7% in variance above that accounted for by knowledge and beliefs. Together, these three classes of variables accounted for 39% of the variance in self-reported adherence, an increase of almost 20% from previous studies (e.g., Horne and Weinman, 2002).

As noted earlier, long term considerations are what drove adherence to preventers. Namely, those most likely to adhere (1) believed that asthma is a long lasting chronic condition, (2) believed that preventer medications are necessary to reduce the progression of the disease in the long term, (3) understood that asthma is a problem with the airways that will worsen over time (pathophysiology) and (4) valued the extent to which a treatment will produce long term effects above other elements of a medication (e.g.,

immediate effects, side effects, and complexity of the regimen). In addition, those who valued long term outcomes were more likely to acknowledge "airway problems" as a cause for their condition and had better knowledge of asthma pathophysiology than those who weighed all attributes equally.

Grouping participants into clusters, as was done here, has some advantages. Until recently, preferences for treatments have been explored either at the aggregate (whole group) level or at the micro level of individual participants (Singh et al., 1998). However, overall group data over-generalizes participants' views and individual differences are lost. Therefore, it is not surprising that interventions based on this "one size fits all" group level approach yields inconsistent results. In contrast, data at the individual level may be oversensitive to individual variation making it impossible for policy makers to systematize intervention. As such, an intermediary step of subgroup analyses is particularly useful. Interventions can then target different patient groups who may use different decision factors based on their distinct goals, needs, and motivations. For example, in the current study, group membership predicted adherence such that those who valued long term outcomes were more adherent than those who weighed all medication attributes equally. Had we not been able to extract subgroups based on preferences, this finding would have been obscured.

It was expected that those inclined to avoid side effects would be less adherent than those focused on long-term outcomes. This prediction was not borne out. One possible reason for this null finding may be decisional uncertainty. That is, the side effect options contained the term "risk" (i.e., "There is a *risk* of major/long term side effects" versus "There is a *risk* of minor/short term side effects"), whereas the long term options

were phrased more definitively ("Your airways *will* be worse in 10 years" versus "Your airways *will* be the same in 10 years"). Research in the area of psychology of decision making has identified many biases that come into play when individuals judge the likelihood of an event (Chapman & Elstein, 2000) and has demonstrated that probability theory is often violated under conditions of uncertainty (Redelmeier, Koehler, Liberman, & Tversky, 1995). Arguably, the term "risk of" evokes more uncertainty than the more decisive wording of the long term outcome options. Accordingly, *certain* maintenance of airway integrity over the long-term may have carried more weight (and hence "predictive punch") than the *possibility* of side effects.

**Main Findings Pertaining to Diary-Reported Adherence**

The two measures of adherence - the medication diary and the MARS scores at one month follow-up- were significantly correlated in the expected direction, but the magnitude of the association ($r_s$= .35) is lower than observed between the MARS and electronic monitoring indices of adherence ($r_s$=.50) (Cohen et al., 2009). Moreover, whereas the MARS scores correlated with many of the hypothesized predictors of adherence, diary scores correlated with none.

One explanation for this pattern of findings is a lack of sufficient variation in the diary scores, which were "0" (indicting 'perfect' compliance) roughly 60% of the time. Another explanation is that the MARS scale used in this study and the diary recording may actually measure different aspects of adherence.

Recent data suggests that adherence is not a uni-dimensional construct (Mora et al., 2011; Clifford et al., 2008). For example, a recent factor analysis of the revised MARS-A 10 item scale revealed two types of intentional non-adherence: (1) stimulus or symptom

driven non-adherence and (2) intentional reduction or avoidance of medications. In the first type of non-adherence, patients use somatic signs as cues to take their medications. In other words, patients' bodies provide them with feedback about the effectiveness of their medications. Items such as "*I only use it when I feel breathless*" and "*I use my inhaler only when my other one doesn't work*" illustrate this construct. The second type of intentional non-adherence is more deliberative, whereby patients make decisions as to whether or not to take their medication based on their internal working models. Items such as "*I alter the dose*" or "*I try to avoid using it*" reflect this more deliberative process.

Unfortunately, Mora et al.'s (2011) version of the MARS (the MARS-A) was not available at the time this study was designed and executed. One could predict that had it been administered, the subscale tapping somatically-cued adherence would have correlated more strongly with the diary measures than the more deliberative subscale, the reasoning being that if patients use their fluctuating symptoms as cues to take their medications, their diary reports, on which they recorded the times they chose to take medications, would reflect this behaviour. To verify this hypothesis, however, future research will need to monitor fluctuations in symptoms that occur in tandem with medication- taking.

Moreover, Mora et al. (2011) found the two subtypes of non-adherence to be only slightly inter-correlated. If the diary recordings more directly tap the somatically-cued adherence behaviours, then we would anticipate only a weak correlation with the MARS measures used in this study, as it mostly gauged the second type of intentional non-adherence. In addition, the adherence behaviours recorded in the diary likely do not reflect the more deliberative, planned adherence decisions tapped by the second factor on

the MARS-A, as it makes sense that this second factor is more influenced by knowledge, beliefs and preferences. This may explain why MARS, and not the diary measures, correlated with the predictors of interest. As is argued in more detail in the sections below, while a macro decision to follow health care recommendations may initiate adherence, it is enacted through the myriad of daily decisions, which may be better reflected in the daily diaries. Perhaps the knowledge, beliefs, and preference variables explored in this study drive the macro more so than the daily decisions, and as such, did not correlate with the diary measures.

**Other Notable Findings**

Although not the main focus of the study, other findings worthy of comment emerged.

**Reported adherence on the MARS increased over time.**

As a group, participants reported higher adherence on the MARS at one month follow up than they did initially, just before being seen by their health care provider at the clinic visit. Without a control group, we cannot really know whether this is due to the Hawthorne effect or due to specific 'interventions' that took place between the two administrations, namely the self-monitoring requirement of the daily diary, or meeting with the clinic physician. Both are plausible mechanisms. With respect to self-monitoring as a potential mechanism, in a non-controlled study, Straka et al. (1997) found that after completing medication diaries, heart disease patients' adherence rates (as gauged by electronic monitors) increased by 9 percent.

However, that the effect was observed only for those visiting the clinic for the first time and not amongst those coming for repeat visits strongly suggests that, rather than

being due to self-monitoring, the meeting with the asthma centre clinician and/or simply the novelty of initiating treatment at a specialty clinic (rather than primary care) provided the new patients an added incentive to adhere. Accordingly, the more plausible explanation, supported by findings reported by DiMatteo et al., (2003) for the increases in MARS scores is that patients' treatment efficacy attitudes were shaped/reinforced during their first visit at the specialty clinic which, in turn, increased their tendency to adhere.

**Discerning preferences.**

Participants' overt ratings of the importance of various attributes of their treatment regimen did not correlate (all *r*'s less than .28) with the preferences revealed through the DCE task. Moreover, had we relied solely on data from the rating scales, subgroup differences would have been obscured. Factor analysis of the rating scales for the entire sample yielded four factors, namely: (1) Efficacy of treatment, (2) Complexity of treatment, (3) Side effects and, (4) Cost, but long term outcomes did not emerge as a factor. Notably, preferences for long term outcomes, inferred from the DCE task, emerged as the dominant predictor of adherence, and none of the explicit rating factors predicted.

Rating scales (which require participants to rate their opinions or attitudes on a numerical or semantic scale) and ranking tasks (which require respondents to give an ordinal ranking of items such that the items that receive the highest ranking are considered most important) are widely used in the health research domain (Ryan et al., 2001; van Helvoort-Postulart, van der Weijden, Dellaert, de Kok, von Meyenfeldt, & Dirksen, 2009). Based on an a systematic literature review of quantitative and qualitative methods for eliciting public preferences for health care, Ryan et al. (2001) argued that

although the ease of both administering and scoring ranking and rating scales makes them attractive, they are limited in that they do not take context into consideration. Moreover, ranking and ratings entail judgments, not choice, and rating one alternative higher than another does not necessarily mean one will choose the former (Payne, Betteman, & Johnson, 1992).

Unlike rating/ranking scales, DCEs, take context and strength of preference into account. Moreover, they assess preferences in a more externally valid way. By comparing options that vary along several attributes at once, respondents are impelled to consider trade-offs. This has important implications for health care resource allocation. Rating or ranking something very highly does not necessarily mean that a health consumer or funder wants to allocate all resources (e.g., funds, efforts) to that consideration at the expense of everything else. This recognition has resulted in the increased use of discrete choice scenarios (which assess trade-offs) in health care research (Ryan, Bate, Eastmond, & Ludbrook, 2001; Ryan & Farrar, 2000; van Til, Stiggelbout, & Ijzerman, 2009). Given that health care provider time is a limited resource, using this methodology to elicit patient preferences may optimize the time spent with health care providers.

As far back as two decades ago, there was a call for psychologists and economists to work more closely together to better explain health choice behaviour and uptake of health services (Phillips & Rosenblatt, 1992). Health economists, interested in exploring market choices, have established useful methods (such as discrete choice experiments) to explore real-world “trade-offs” of medication choices. Yet, classic economic theory cannot account for when individuals make irrational choices that seem not to logically balance costs against benefits and act/choose so as to maximize their personal advantage (Phillips

et al., 2002). Behavioral economists and cognitive psychologists, however, have identified systematic 'non-rational' yet perfectly understandable biases (e.g., representativeness and availability) shown to play out in medical decision making (Dawson & Arkes, 1987). There are also biases (e.g., hindsight bias and confirmation bias) that affect the judged probability of an adverse health event, as well as the judged utility (value) of a given outcome (e.g., framing effects, preference reversals, sunk cost bias, decision weights, omission bias, and regret) (Chapman & Elstein, 2000). Therefore, the combination of economic methodology to identify what decisions people make, psychological research identifying how people come to the decisions as well as how to rectify problematic biases will prove extremely useful.

**Clinical Implications**

The value of a given theory is enhanced when it can serve a pragmatic function – in this case, improve adherence. Leventhal and Cameron (1987) suggested that the Common Sense Model of Illness (CSM) can be incorporated into three types of educational interventions. First, in "communication style"- focused interventions, health care providers use their relationship with patients to help them accept a message. In essence, belief in both the message and the messenger are presumed to encourage behaviour. Second, cognitive-focused interventions emphasize less the relationship between the parties and more the cost-benefit analysis of beliefs (health threat versus behaviour) as motivating factors. Finally, interventions that focus on self-regulation emphasize patients as an active problem solvers and their ability to meet the health challenge. While interventions guided by these models do tend to improve patients' abilities to manage their disorder, the relative importance of each component as the active ingredient remains

unclear (van Dumalen et al., 2004). Moreover, others (Horne et al., 2007) have suggested that it is simply beliefs, not education, that motivates behaviour change.

However, our findings suggest that beliefs and knowledge alone are not enough, and that patients' goals and preferences for treatment also drive adherence. Psychologists have long advocated using patient-defined goals to guide treatment and recently, medical experts have begun to acknowledge the importance of incorporating goals into treatment (Charles, Gafni, & Whelen, 1999). For example, Wilson et al., (2010) randomized patients with asthma to either a treatment regimen wherein clinicians and patients worked together to accommodate patients' goals and preferences or a clinical decision group in which patients' goals were not elicited. Both groups received asthma education and two in-person and three phone encounters. At one year follow-up, those patients whose preferences and goals were targeted were more adherent to their preventer medication and used their rescue medication significantly less than the standard care group at two year follow-up.

It may be clinically useful to conceptualize adherence to asthma medications as a two-tier process, wherein patients make both macro (i.e., "Will I fill my prescription?) as well as micro (i.e., "Shall I take my preventer medication this morning?") level decisions. Preferences for treatment as well as knowledge and beliefs likely target macro level decisions. Once the macro decision has been made, behavioural factors, such as patients' skill and ability to take the medications likely play a more important role. Targeting patients' behavioural abilities has been shown to be imperative for the prediction and promotion of sexual and reproductive health behaviours (Bryan, Fisher, Fisher, & Murray, 2000; Cornman, Schmiege, Bryan, Benziger, & Fisher, 2007; J. Fisher, Fisher,

Bryan, & Misovich, 2002; W. Fisher, Williams, Fisher, & Malloy, 1999). For patients with asthma, current treatment guidelines suggest using written asthma action plans as well as providing education about the techniques associated with inhaler use. These strategies have been shown to be moderately effective (Gibson & Powell, 2004), likely because patients must first make a decision about whether or not they are going to adhere at all; a decision based on their beliefs and preferences. Notably, the technique subscale of the asthma knowledge scale used in this study was not correlated with adherence on the MARS. Again, it appears that the MARS tap higher order (macro) decisions and not daily medication decisions.

As such, Motivational Interviewing (MI) strategies, emergent from the psychological literature, may be particularly useful for targeting patient health care preferences and goals that need to be addressed before behavioural skills are taught. MI is a method for enhancing change behaviours by exploring and resolving ambivalence (Miller & Rollnick, 2002). Incorporating MI into interventions can double the effect size of an intervention and improve retention and adherence (Burke, Arkowitz, & Menchola, 2003; Hettema, Steele, & Miller, 2005). However, it should be noted that motivational interviewing techniques tend to focus on ambivalence around changing behaviour to achieve one given goal, in part, by helping people address the actual costs of the behaviour change (i.e., Although I want to lose weight, and know that one of the ways I can do so is exercise, I'll sweat when I exercise, and I hate the sensation of sweating). Horne et al. (2007) note, however, that patients often present with what appear to be contradictory goals. For example, a patient might have as a goal to reduce symptoms of the disease but might equally want to reduce the risk of side-effects. If a given medication

equally promises/threatens both outcomes, then this patient understandably is in a bind. However, individuals often are unaware of the sources of their ambivalence and the present study presents a means – DCE- by which to elucidate (for patients, their practitioners, and health system planners), the trade-offs individuals are willing to make.

**Main Limitation: The Dependent Measure - Adherence.**

**Adherence is likely overestimated**.

Measurement of adherence is both controversial and fraught with methodological challenges. Self-report surveys, while the most widely-used in research, tend to underestimate non-adherence by approximately 20 percent (Horne & Weinman, 1999), probably because patients are loathe to admit (to themselves and others) that they do not follow their health care providers' prescriptions. Moreover, diary records have been shown to overestimate medication use (as gauged by electronic monitoring) by more than 50% (WHO, 2003). There is, however, no ideal way to measure adherence (Clifford, Barber, & Horne, 2008) and it is recommended that convenience, participant acceptability, and cost be taken into consideration when deciding which measure to use (Vitolins, Rand, Rapp, Ribisl, & Sevick, 2000). Given logistic constraints, we chose to employ self-report measures of adherence, which reviews of the literature (Haynes et al., 1980; Stephenson, Rowe, Haynes, Macharia, & Leon, 1993; Bende et al., 2003) have shown compare well with more objective measures electronic records and pharmacy reports.

Our primary outcome measure (MARS) was significantly negatively skewed - people reported a high degree of adherence. But despite the high scores, 83% of participants in our sample admitted to sometimes, always, or often engaging in at least

one of the nine non-adherent behaviours. In fact, our sample more readily acknowledged non-adherence than did that of Horne and Weinman (2002) who report that only 74% of their sample admitted to these behaviours. And, even with this distributional challenge, Horne and Weinman (2007) still observed statistically and conceptually meaningful relationship between adherence and their predictors of interest, as did we. The emergence of statistically significant associations despite the distributional properties of the dependent variable suggests that the relationships are quite robust, and if anything, the strength of the predictors is likely underestimated. Accordingly, it may be useful in the future to use more objective measures of adherence (though they can be relatively expensive monetarily and effort-wise) to explore these relationships further.

**Failing to differentiate intentional and non-intentional non-adherence.**

There are different types of non-adherence including erratic non-adherence (e.g., non-adherence due to forgetfulness or changing schedules), unwitting non-adherence (i.e., unintentional non-adherence stemming from a lack of patient understanding about how to take their medications) and intelligent non-adherence (i.e., non-adherence stemming from a reasoned choice not to take medication) (WHO, 2003). Clifford, Barber and Horne (2008) argue that the hundreds of factors hypothesized to influence adherence can be categorized into intentional or non-intentional factors. Non-intentional factors are synonymous with unwitting and erratic non-adherence factors described above, in that patients may inadvertently be non-adherent either because they have failed to understand the skills necessary to take their medications or they cannot manage to take it. Intentional non-adherence, on the other hand, is influenced by patients' beliefs, knowledge and motivation. Notably, intentional and nonintentional adherence factors may overlap. For

example, patients who have fewer beliefs about the necessity of their medication may be less motivated to take it and, as a result, forget to take it more often.

Clifford et al. (2008) demonstrated differences in treatment beliefs among intentional and unintentional adherers. Compared to adherers, intentional (but *not* unintentional non-adherers) believed less in the necessity of and had more concerns about their prescribed medications. A limitation of the current study is that the MARS contained only one item tapping unintentional non-adherence (*I forget to use it*) which was significantly correlated (*r*'s ranging from .30 to .60) with the other items on the scale (with the exception of "*I use it only as a reserve*"), and so it was not possible to discern the differential predictors of intentional and non-intentional adherence in this sample. If Clifford et al.'s (2008) measure had been used in this study, one would hypothesize that knowledge, beliefs and preferences would predict intentional but not non-intentional non-adherence.

**Future Directions**

The current study was novel in its integration of theory and methodology from a number of disciplines which, when combined, suggest that, to the extent to which individuals with asthma understand and believe in the long term nature of their disorder and the need for medications and value long term outcomes, they will be likely to adhere to their preventer medication. While these findings provide a first step to better understanding patient decision making in the context of asthma medication adherence, more work has to be done to extend the scope of inquiry. In particular, examining a broader number of attributes and levels, expanding the focus to other aspects of self-care regimens, increasing the length of the prospective sampling period and exploring the

reciprocal relationships between the variables are all potential future research directions. Each is considered below.

When developing a discrete choice experiment it is essential to ensure that the design involves an appropriate range of levels which capture salient elements of the attributes. The levels must be plausible and clinically relevant (Lancsar & Louviere, 2008). The attributes chosen in this study were dictated by the study hypotheses and the attribute levels were chosen so as to be able to generate cluster scores to subsequently be used to predict adherence. Consequently, only binary attribute levels were employed. While the binary attribute is the most common DCE design (Street & Bourgess, 2007), the study might have benefited from the inclusion of more nuanced attribute levels. Therefore, while the design in the current study met the necessary criteria (i.e., all attributes and levels were salient, clinically plausible, and relevant), future research may improve our understanding of the effect of preferences on adherence behaviours by incorporating a greater range of preference options.

According to Osterberg and Blaschke (2005), patients with chronic conditions demonstrate consistently low rates of adherence that drop dramatically after the first six months of treatment. Adherence is of interest largely (if not only) because it should lead to decreased morbidity. The limited length of the follow-up period (one month) precluded our finding any association between knowledge, attitudes and preferences and changes in asthma quality of life, as mediated by adherence. As a result, future research involving a longer time frame would be useful for exploring this relationship.

Given the gravity of the problems associated with asthma medication non-adherence, this study was focused specifically on adherence to preventer medication. But, lifestyle

factors, including getting rid of pets, exercising to lose weight to improve lung functioning, or quitting smoking are also clinically relevant "behavioural prescriptions". It is quite plausible that beliefs and preferences may play an even greater role in explaining adherence to these recommendations as they involve more complex trade-offs off people's values (i.e., keeping my pet vs. maintaining my lung function). As such, future research should focus not only on the predictors of medication adherence, but also on what drives people's lifestyle modification decisions.

Finally, this study examined the additive effects of patient preferences on adherence. However, the reciprocal nature of the relationship between knowledge, beliefs and preferences remains unclear. Future research would benefit from exploring interaction effects between these three important constructs.

**Overall Summary and Conclusion**

Adherence is a complex and multifaceted phenomenon. The consequences of non-adherence are significant and include increases in health care costs and poor medical outcomes. Hundreds of factors have been hypothesized to be associated with adherence across a number of health conditions, treatments, and populations (Clifford et al., 2008) and many health care providers and policy officials have attempted to incorporate the associated factors into intervention programs. To date, however, costly and time consuming intervention programs have been met with only modest success.

In an attempt to improve the understanding of patient non-adherence, this thesis integrated the theory and methods of three disciplinary literatures, namely, nursing/public health, psychology and economics, to explore the additive effects of knowledge, beliefs and preferences on medication adherence in a sample of patients with asthma. It was

predicted that long term factors- understanding the chronic nature of the disorder, the necessity for medications to stymie the progression of the disease and valuing long term effectiveness of medications above immediate symptom alleviation, treatment complexity and side effects- would improve adherence reports.

A notable finding is that participants who understood that their asthma was a chronic pathophysiological condition which could deteriorate if preventers were not taken as prescribed were more adherent to their medication than those who did not hold this knowledge and belief. This strongly suggests that, to improve patient adherence to asthma preventer medications, patients should be helped to understand *why* they require these medications.

In a recent position paper, Horne et al. (2007) stated that "In the real world where patients make choices that may reflect conflicting priorities, asthma still imposes a considerable burden on healthcare systems" (p. 9). Identifying the sources of conflicting priorities for each individual, however, is impractical for developing systematized interventions. On the other hand, eliciting preferences of overall patient groups over-generalizes and limits the clinical utility of findings. An intermediate step, subgroup analysis, is much more practical. This study was among the first to assess preferences at the intermediate step of subgroup levels and represents the first attempt to use latent cluster analyses of data from discrete choice experiments to uncover previously unidentified heterogeneity among a sample of patients with asthma.

Identifying what is important to patients and ultimately working collaboratively towards valuing long term outcomes will improve adherence rates among patients with asthma. In designing intervention programs, policy makers must understand that

knowledge is only half of the story. Programs should focus on making sure patients understand the physiology and functional limitations of asthma, why medications are required, and help guide them to value long term asthma outcomes. After all, our findings suggest that if the *why* is clear, patients are more likely to adhere.

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## Appendix A

### Results from Expert Panel and Additional Consultation

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Pathophysiology | 1. People with asthma can have swollen and inflamed airways even when they feel normal (T) | 3.62 | - Would include "to a much lesser degree b/c otherwise implies lots of inflammation<br>- Replace normal with well | People with asthma can have swollen and inflamed airways even when they feel well (T) | | People with asthma can have swollen and inflamed airways even when they feel well (T) |
| Pathophysiology | 2. During an asthma attack, the muscles around the airways tighten and the airways become narrow (T) | 3.90 | | | | During an asthma attack, the muscles around the airways tighten and the airways become narrow (T) |
| Pathophysiology | 3. Having swollen airways does not increase the risk of having an asthma attack (F) | 3.43 | - Reword to true statement (4 comments)<br>-Suggest: "Having swollen airways increases the risk of having an asthma attack" | Having swollen airways increases the risk of having an asthma attack (T) | | Having swollen airways does not increase the risk of having an asthma attack (F) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Pathophysiology | 4. Asthma is a disease that comes and goes (F) | 3.43 | -"vary in level of symptoms from none to quite frequent, but never go away completely"<br>-"can be true"<br>-"not sure I am interpreting this correctly- I suspect most people associate the disease with symptoms"<br>- Pam's suggestion, replace with : Asthma is a chronic condition | Asthma symptoms come and go but the disease is always there. (T)<br><br>OR:<br><br>Asthma is a disease that does not last for a long period of time. (F) | The comments are correct BUT we are not asking a scientific audience and don't expect a scientifically correct answer. So yes, asthma can go into remission but if you are asking the question to someone with current asthma the correct lay answer is that it does not go away, it is a chronic condition.<br>I like the second question. | Asthma is a disease that does not last for a long time. |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Medications and Their Effects | 5. The purpose of steroid medication inhalers is to stop an asthma attack when it happens (F) | 3.57 | - Consider simplifying (steroid inhalers stop asthma attacks when they happen)<br>- "Depends on if the attack is due to bronchoconstriction, exacerbation, or inflammation"<br>- "ICS, in fact, may diminish worsening asthma symptoms (if taken regularly) or if combined with LABA (ie symbicort SMART). " | The purpose of an inhaled steroid (controller) is to stop an asthma attack when it starts (F) | An inhaled steroid (controller) will quickly stop an asthma attack when it starts. (F) | The purpose of steroid medication inhalers is to stop an asthma attack when it happens. (F) |
| Medications and Their Effects | 6. Controller inhalers prevent asthma attacks (T) | 3.57 | - Do people know what a controller medication is?<br>- Suggest replacing prevent with reduce | Inhaled steroids (controllers) prevent asthma attacks (T) | | Inhaled steroids (controllers) prevent asthma attacks. (T) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Medications and Their Effects | 7. People with asthma do not need to take their daily steroid medication if they feel normal (F) | 3.62 | - Specify inhaled steroid<br>-"if their breathing feels normal"<br>-Replace normal with well or have no symptoms | People with asthma do not need to take their daily inhaled steroids (controller) if they feel well (F) | | People with asthma do not need to take their daily inhaled steroids (controller) if they feel well. (F) |
| Medications and Their Effects | 8. Quick relief medication should be taken every day (F) | 3.86 | - Add: …should be taken every day even if you are feeling well<br>-"This is true only if the steroid is needed to control the eosinophilic component" | Quick relief medication should be taken every day, even if people are feeling well (F) | | Quick relief medications should be taken every day, even if people are feeling well. (F) |
| Medications and Their Effects | 9. People with asthma should wait until their symptoms are really bad before using a quick relief medication (F) | 3.90 | | | | People with asthma should wait until their symptoms are really bad before using quick relief medication. (F) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Medications and Their Effects | 10. People may not notice improvements in their breathing for 1-4 weeks after they start using inhaled steroids (T) | 3.52 | -" With adequate steroid treatment, improvement occurs rapidly- within days. By a week it is near maximal"<br>- "People may notice improvements within days"<br>-Suggest: "may not notice improvements in their symptoms (cough, wheeze, SOB…)" | | Leave the same. | People may not notice improvements in their breathing for 1-4 weeks after they start using inhaled steroids. (T) |
| Medications and Their Effects | 11. It is okay to take inhaled steroid medication only when people notice themselves wheezing (F) | 3.57 | - "What about people with mild intermittent asthma who are told to start inhaled ICS only if increase in symptoms" | It is ok to take inhaled steroids (controllers) only when people notice their symptoms getting worse (F) | Patients treated on an interval basis are the minority. | It is okay to take inhaled steroids (controllers) only when people notice their symptoms getting worse. (F) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Medications and Their Effects | 12. Steroid inhalers will relieve an asthma attack within 20 minutes (F) | 3.76 | | Inhaled steroids will relieve an asthma attack within 20 minutes | | Inhaled steroids will relieve an asthma attack within 20 minutes. (F) |
| Technique | 13. People with asthma should breathe out partially, but not fully, just before taking their medication (F) | 3.57 | | | | People with asthma should breathe out partially, but not fully, just before taking their medication (F) |
| Technique | 14. People with asthma should hold their breath for 10 seconds after each puff of their inhaler (T) | 3.71 | - "No evidence that holding breath for 10 seconds affects drug distribution"<br>-Add: "should try and hold"<br>-Pam suggests: 8-10 seconds to be consistent with clinic | People with asthma should try to hold their breath for 8-10 seconds after each puff of their inhaler | | People with asthma should try to hold their breath for 8-10 seconds after each puff of their inhaler. (T) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Technique | 15. People with asthma should wait about one minute between puffs of their quick relief medication (T) | 3.32 | - "Not just for quick relief. Revise to: '… between puffs of their medication when taking 2 or more puffs from the same inhaler' "<br>- 30 seconds more reasonable (esp. at St. Joe's clinic)<br>- What about when with a Turbuhaler- this does not apply | People with asthma should rinse and gargle after each use of their inhaled steroid (T) | The initial question is too problematic for the reasons cited.<br><br>However, (according to the nurse) we do try to recommend at the clinics, therefore, I would leave it in. | 1. People with asthma should wait about one minute between puffs of their quick relief medication (T)<br><br>2. People with asthma should rinse and gargle after each use of their inhaled (controller) steroid. (T) |
| Symptoms | 16. Frequent coughing can be a symptom of asthma (T) | 3.86 | - Cough at night is more diagnostic | | | Frequent coughing can be a symptom of asthma. (T) |
| Symptoms | 17. Asthma may cause wheezing during exercise (T) | 4.00 | | | | Asthma may cause wheezing during exercise. (T) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Symptoms | 18. It is possible for someone's asthma to be worse without noticing a change in their breathing (T) | 3.81 | | | | It is possible for someone's asthma to be worse without them noticing a change in their breathing. (T) |
| Environmental Triggers and Controls | 19. People with asthma can usually control their symptoms by taking medicine and avoiding things that make their asthma worse (T) | 3.86 | - Suggest adding "appropriate medication"<br>- Replace medicine with "medication as prescribed"<br>-Replace "things that make asthma worse" with triggers | Split:<br>1. People with asthma can usually control their symptoms by taking the appropriate medications<br>2. People can usually control their symptoms by avoiding things (triggers) that make their asthma worse | | 1. People with asthma can usually help control their symptoms by avoiding things (triggers) that make their asthma worse. (T)<br>2. People with asthma can usually help control their symptoms by taking the appropriate medications. (T) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Environmental Triggers and Controls | 20. Keeping bedroom windows open at night will help prevent asthma attacks (F) | 3.86 | | | | Keeping bedroom windows open at night will help prevent asthma attacks. (F) |
| Environmental Triggers and Controls | 21. Bedrooms are the most important room to keep free of dust and animal fur or feathers (T) | 3.71 | - True if allergic to those things<br>-Factually incorrect<br>-only if patient is allergic to dust and animal dander | Remove and replace with: Cold air can make asthma symptoms worse (T) | Taking steps to reduce airborne particles such as dust and animal dander can improve asthma symptoms in people allergic to them. (T) | Cold air can make asthma symptoms worse. (T) |
| Environmental Triggers and Controls | 22. Carpets that smell moldy can trigger asthma (T) | 3.48 | -"smells don't trigger asthma"<br>-change can to might<br>-"molds are over-rated" | Remove and replace with more generic: Stress is never a trigger for worsening asthma symptoms (F) | Molds can trigger asthma symptoms in some people. (T) | Molds can trigger asthma symptoms in some people. (T) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Environmental Triggers and Controls | 23. Covering pillows and mattresses with plastic covers can improve asthma (T) | 3.33 | - "We don't recommend this"<br>-"True only for dust mite allergy" | Remove | We don't recommend this at the clinic so patients will not know about it. | REMOVE |
| Other Asthma Facts | 24. Untreated asthma can cause death (T) | 3.81 | | | | Untreated asthma can cause death. (T) |
| Other Asthma Facts | 25. Asthma can be completely cured (F) | 3.67 | -Drop completely because tautological<br>-"This is true when it is caused by avoidable allergens or occupational sensitizers"<br>-What about post-infectious asthma- isn't that cured after the infection?<br>-"use other wording to prevent 'cured' from being confused with 'controlled'" | | | Asthma can be cured. (F) |
| Other Asthma Facts | 26. People with asthma should avoid exercise (F) | 3.90 | | | | People with asthma should avoid exercise. (F) |

| Domain (Based on Schaffer and Yarandi) | Survey Question | Expert Rating | Expert Comments | Suggested Change | Consultation Comments | Final Question |
|---|---|---|---|---|---|---|
| Other Asthma Facts | 27. It does not bother a person's asthma when others smoke cigarettes around them (F) | 3.76 | -Perhaps rephrase: "second hand smoke is irritating to a person with asthma's airways even if it does not worsen symptoms" - | Second hand smoke can make a person's asthma worse, even if people do not notice a change in their symptoms(T) | | Being around others who smoke does not bother a person's asthma, as long as they don't smoke themselves. (F) |
| Other Asthma Facts | 28. Taking an antibiotic such as penicillin will help most bad asthma attacks (F) | 3.81 | - Drop "such as penicillin" | | | Taking an antibiotic such as penicillin will help most bad asthma attacks. (F) |
| Other Asthma Facts | 29. If asthma attacks stop, it means that the asthma has gone away (F) | 3.71 | - Near duplicate of 25 - "Not sure if saying asthma attacks stop means asthma is gone when patients still experience symptoms" | | When someone's asthma attack is over it means that the asthma has gone way. | When someone's asthma attack is over it means that the asthma has gone way. (F) |
| Other Asthma Facts | 30. If a person does not have asthma by the time they are 40, they will never get it (F) | 3.62 | - Suggest: "By the age of 40" | If a person does not have asthma by age 40, they will never get it (F) | | If a person does not have asthma by age 40, they will never get it. (F) |

## Appendix B

## Asthma Knowledge Questionnaire

Please place a mark in the box marked "TRUE" for statements you believe are correct, "FALSE" for those statements that are not correct, and "UNSURE" if you do not know if the statement is true or false.

| | TRUE | FALSE | UNSURE |
|---|---|---|---|
| 1. People with asthma can have swollen and inflamed airways even when they feel well | ☐ | ☐ | ☐ |
| 2. Asthma is a disease that does not last for a long time | ☐ | ☐ | ☐ |
| 3. Quick relief medications should be taken every day, even if people are feeling well | ☐ | ☐ | ☐ |
| 4. People with asthma should try to hold their breath for 8-10 seconds after each puff of their inhaler | ☐ | ☐ | ☐ |
| 5. It is possible for someone's asthma to be worse without them noticing a change in their breathing | ☐ | ☐ | ☐ |
| 6. Molds can trigger asthma symptoms in some people | ☐ | ☐ | ☐ |
| 7. Asthma can be cured | ☐ | ☐ | ☐ |
| 8. Being around others who smoke does not bother a person's asthma, as long as they don't smoke themselves | ☐ | ☐ | ☐ |
| 9. Inhaled steroids (controllers) prevent asthma attacks | ☐ | ☐ | ☐ |
| 10. People with asthma should wait until their symptoms are really bad before using a quick relief medication | ☐ | ☐ | ☐ |
| 11. During an asthma attack, the muscles around the airways tighten and the airways become narrow | ☐ | ☐ | ☐ |
| 12. People with asthma should rinse and gargle after each use of their inhaled (controller) steroid | ☐ | ☐ | ☐ |
| 13. A person with asthma can use a combination inhaler for quick relief, even if they do not use it | ☐ | ☐ | ☐ |

every day

| | | | |
|---|---|---|---|
| 14. Taking an antibiotic such as penicillin will help most bad asthma attacks | □ | □ | □ |
| 15. People may not notice improvements in their breathing for 1-4 weeks after they start using inhaled steroids | □ | □ | □ |
| 16. Cold air can make asthma symptoms worse | □ | □ | □ |
| 17. Frequent coughing can be a symptom of asthma | □ | □ | □ |
| 18. A combination inhaler includes two types of medication to control asthma | □ | □ | □ |
| 19. Having swollen airways does not increase the risk of having an asthma attack | □ | □ | □ |
| 20. The purpose of steroid medication inhalers is to stop an asthma attack when it happens | □ | □ | □ |
| 21. People with asthma can usually help control their symptoms by taking the appropriate medications | □ | □ | □ |
| 22. People can usually help control their symptoms by avoiding things (triggers) that make their asthma worse | □ | □ | □ |
| 23. People with asthma should avoid exercise | □ | □ | □ |
| 24. When someone's asthma attack is over it means that the asthma has gone way | □ | □ | □ |
| 25. It is okay to take inhaled steroids (controllers) only when people notice their symptoms getting worse | □ | □ | □ |
| 26. Inhaled steroids will relieve an asthma attack within 20 minutes | □ | □ | □ |
| 27. People with asthma should wait about one minute between puffs of their quick relief medication | □ | □ | □ |
| 28. People with asthma do not need to take their daily inhaled steroids (controller) if they feel well | □ | □ | □ |

| | | | |
|---|---|---|---|
| 29. People with asthma should breathe out partially, but not fully, just before taking their medication | ☐ | ☐ | ☐ |
| 30. Asthma may cause wheezing during exercise | ☐ | ☐ | ☐ |
| 31. Keeping bedroom windows open at night will help prevent asthma attacks | ☐ | ☐ | ☐ |
| 32. Untreated asthma can cause death | ☐ | ☐ | ☐ |
| 33. If a person does not have asthma by age 40, they will never get it | ☐ | ☐ | ☐ |
| 34. Chest tightness is a common symptom of asthma | ☐ | ☐ | ☐ |
| 35. People with asthma get relief from their symptoms at night | ☐ | ☐ | ☐ |
| 36. Asthma attacks often come on suddenly without any warning | ☐ | ☐ | ☐ |

## Appendix C

## Rating Scale

There are different things people have to weigh when deciding whether or not to use an inhaler. For example, while some people with asthma may worry about a medication's side effects, they feel that the benefits from the medication are worth the risk. Others are not so sure.

We are interested in what kinds of things you consider when deciding whether or not to use an inhaler. Trying to keep the list of things below in mind, please rate on a scale of 1-10, the importance of each of the following.

| 1<br><br>Least Important | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br><br>Most Important |
|---|---|---|---|---|---|---|---|---|---|

1. The number of different inhalers I need to take _____
2. Having to take an inhaler every day _____
3. Being able to take an inhaler only when I need it _____
4. Possible short-term side-effects of the inhaler _____
5. Possible long- term side-effects of the inhaler _____
6. Risk of addiction to the inhaler _____
7. The inhaler can take my symptoms away within minutes _____
8. The inhaler can help keep my asthma from getting worse over the next 10 years

   ___
9. The inhaler can reduce how often I get asthma attacks over the next six months

   ___
10. The cost of the inhaler _____

## Appendix D

### Discrete Choice Experiment Scenarios

Your Preferences for Asthma Treatments (Card 1 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | The Same | Worse |
| Over the next 6 months, you will have… | Fewer asthma attacks | The same number of asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 5 minutes | Symptom relief within 30 minutes |
| The dose of steroids in your medication will be… | Low | High |
| You take your medication … | Every day at set times and extra if you need it | Only when you need it |
| You will get… | 2 Inhalers | 1 Inhaler |
| Because of your medication, you may experience… | Major and/or long-term side effects | Minor and/or short-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 2 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | The Same | Worse |
| Over the next 6 months, you will have… | The same number of asthma attacks | Fewer asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 30 minutes | Symptom relief within 5 minutes |
| The dose of steroids in your medication will be… | High | Low |
| You take your medication … | Every day at set times and extra if you need it | Only when you need it |
| You will get… | 2 Inhalers | 1 Inhaler |
| Because of your medication, you may experience… | Minor and/or short-term side effects | Major and/or long-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 3 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | Worse | The Same |
| Over the next 6 months, you will have… | Same number of asthma attacks | Fewer asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 5 minutes | Symptoms relief within 30 minutes |
| The dose of steroids in your medication will be… | Low | High |
| You take your medication … | Only when you need it | Every day at set times and extra if you need it |
| You will get… | 1 Inhaler | 2 Inhalers |
| Because of your medication, you may experience… | Minor and/or short-term side effects | Major and/or long-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 4 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | The Same | Worse |
| Over the next 6 months, you will have… | Fewer asthma attacks | The same number of asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 5 minutes | Symptom relief within 30 minutes |
| The dose of steroids in your medication will be… | High | Low |
| You take your medication … | Only as needed | Every day at set times and extra if you need it |
| You will get… | 1 Inhaler | 2 Inhalers |
| Because of your medication, you may experience… | Minor and/or short-term side effects | Major and/or long-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 5 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | Worse | The Same |
| Over the next 6 months, you will have… | Fewer asthma attacks | The same number of asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 30 minutes | Symptom relief within 5 minutes |
| The dose of steroids in your medication will be… | Low | High |
| You take your medication … | Every day at set times and extra if you need it | Only when you need it |
| You will get… | 1 Inhaler | 2 Inhalers |
| Because of your medication, you may experience… | Minor and/or short-term side effects | Major and/or long-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 6 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | The Same | Worse |
| Over the next 6 months, you will have… | The same number of asthma attacks | Fewer asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 30 minutes | Symptom relief within 5 minutes |
| The dose of steroids in your medication will be… | Low | High |
| You take your medication … | Only when you need it | Every day at set times and extra if you need it |
| You will get… | 1 Inhaler | 2 Inhalers |
| Because of your medication, you may experience… | Major and/or long-term side effects | Minor and/or short-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 7 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | Worse | The Same |
| Over the next 6 months, you will have… | The same number of asthma attacks | Fewer asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 5 minutes | Symptom relief within 30 minutes |
| The dose of steroids in your medication will be… | High | Low |
| You take your medication … | Every day at set times and extra if you need it | Only when you need it |
| You will get… | 1 Inhaler | 2 Inhalers |
| Because of your medication, you may experience… | Major and/or long-term side effects | Minor and/or short-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

## Your Preferences for Asthma Treatments (Card 8 of 8)

When considering your asthma treatment program, if you were offered the choice between program A or B, which would you most prefer?

| | Program A | Program B |
|---|---|---|
| In 10 years, your asthma will be… | Worse | The Same |
| Over the next 6 months, you will have… | The same number of asthma attacks | Fewer asthma attacks |
| Your treatment program will provide you with… | Symptom relief within 30 minutes | Symptom relief within 5 minutes |
| The dose of steroids in your medication will be… | High | Low |
| You take your medication … | Only when you need it | Every day at set times and extra if you need it |
| You will get… | 2 Inhalers | 1 Inhaler |
| Because of your medication, you may experience… | Major and/or long-term side effects | Minor and/or short-term side effects |

Please tick the box (√) below to indicate which treatment (A or B) you would choose.

Remember, you may have to select some features you do not like because, all things considered, you prefer it over the other treatment.

| A | B |
|---|---|
| | |

# Appendix E

## Pilot Study Ethics Approval


**Office of Research Ethics**

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

**Use of Human Subjects - Ethics Approval Notice**

**Principal Investigator:** Dr. L. Swartzman
**Review Number:** 16500E **Review Level:** Expedited
**Review Date:** September 30, 2009
**Protocol Title:** Measuring asthma self-management knowledge and preferences for treatment: A pilot study
**Department and Institution:** Psychology, University of Western Ontario
**Sponsor:** CANADIAN INSTITUTE OF HEALTH RESEARCH
**Ethics Approval Date:** November 03, 2009 **Expiry Date:** January 31, 2010
**Documents Reviewed and Approved:** UWO Protocol, Letter of Information and Consent.
**Documents Received for Information:**

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert

## Appendix F

### Proportion of Sample that Responded Correctly, Incorrectly or was Unsure of Responses to Knowledge Questionnaire Items

| Category | Item | % Correct | % Incorrect | % Unsure |
|---|---|---|---|---|
| Pathophysiology | 2. Asthma is a disease that does not last for a long time (F) | 94.6 | 1.8 | 3.6 |
| | 24. When someone's asthma attack is over it means that the asthma has gone away (F) | 91.1 | 5.4 | 17.9 |
| | 11. During an asthma attack, the muscles around the airways tighten and the airways become narrow (T) | 89.3 | 3.6 | 7.1 |
| | 33. If a person does not have asthma by age 40, they will never get it (F) | 85.5 | 1.8 | 12.7 |
| | 32. Untreated asthma can cause death (T) | 78.6 | 8.9 | 12.5 |
| | 1. People with asthma can have swollen and inflamed airways even when they feel well (T) | 75 | 5.4 | 19.6 |

| Category | Item | % Correct | % Incorrect | % Unsure |
|---|---|---|---|---|
| | 19. Having swollen airways does not increase the risk of having an asthma attack (F) | 75 | 7.1 | 17.9 |
| | 5. It is possible for someone's asthma to be worse without them noticing a change in their breathing (T) | 66.1 | 16.1 | 17.8 |
| | 7. Asthma can be cured (F) | 64.3 | 1.8 | 33.9 |
| Medication | 21. People with asthma can usually help control their symptoms by taking the appropriate medications (T) | 98.2 | 1.8 | 0 |
| | 10. People with asthma should wait until their symptoms are really bad before using a quick relief medication (F) | 92.9 | 1.8 | 5.4 |
| | 28. People with asthma do not need to take their daily inhaled steroids if they feel well (F) | 91.1 | 7.1 | 1.8 |

| Category | Item | % Correct | % Incorrect | % Unsure |
|---|---|---|---|---|
| | 18. A combination inhaler includes two types of medication to control asthma (T) | 67.9 | 10.7 | 21.4 |
| | 25. It is okay to take inhaled steroids only when people notice their symptoms getting worse (F) | 66.1 | 16.1 | 17.9 |
| | 14. Taking an antibiotic, such as penicillin, will help most bad asthma attacks (F) | 64.3 | 5.4 | 30.4 |
| | 3. Quick relief medications should be taken every day, even if people are feeling well (F) | 58.9 | 26.8 | 14.3 |
| | 20. The purpose of steroid medication inhalers is to stop an asthma attack when it occurs (F) | 50 | 32.1 | 17.9 |
| | 9. Inhaled steroids (controller) prevent asthma attacks (T) | 44.6 | 35.7 | 19.6 |

| Category | Item | % Correct | % Incorrect | % Unsure |
|---|---|---|---|---|
| | 15. People may not notice improvements in their breathing for 1-4 weeks after they start using inhaled steroids (T) | 37.5 | 26.8 | 35.7 |
| | 26. Inhaled steroids will relieve an asthma attack within 20 minutes (F) | 37.5 | 32.1 | 30.4 |
| | 13. A person with asthma can use a combination inhaler for quick relief, even if they do not use it everyday (F) | 12.5 | 62.5 | 25 |
| Technique | 12. People with asthma should rinse and gargle after each use of their inhaled steroid (T) | 94.6 | 1.8 | 3.6 |
| | 4. People with asthma should try to hold their breath for 8-10 seconds after each puff of their inhaler (T) | 93 | 5.4 | 1.8 |
| | 29. People with asthma breathe out partially, but not fully, just before taking their medication (F) | 67.9 | 19.6 | 12.5 |

| Category | Item | % Correct | % Incorrect | % Unsure |
|---|---|---|---|---|
| | 27. People with asthma should wait about one minute between puffs of their quick relief medication (T) | 60.7 | 32.1 | 7.1 |
| Environmental Triggers | 22. People can usually help control their symptoms by taking avoiding things that make their asthma worse (T) | 98.2 | 1.8 | 0 |
| | 6. Molds can trigger asthma symptoms in some people (T) | 96.4 | 0 | 3.6 |
| | 8. Being around others who smoke does not bother a person's asthma, as long as they don't smoke themselves (F) | 94.6 | 1.8 | 3.6 |
| | 16. Cold air can make asthma symptoms worse (T) | 94.5 | 1.8 | 3.6 |
| | 23. People with asthma should avoid exercise (F) | 92.9 | 5.4 | 1.8 |

| Category | Item | % Correct | % Incorrect | % Unsure |
|---|---|---|---|---|
| | 31. Keeping bedroom windows open at night will help prevent asthma attacks (F) | 64.3 | 8.9 | 12.5 |
| Symptoms | 30. Asthma may cause wheezing during exercise (T) | 94.6 | 1.8 | 3.6 |
| | 35. People with asthma get relief from their symptoms at night (F) | 93.3 | 3.3 | 3.4 |
| | 34. Chest tightness is a common symptom of asthma (T) | 90 | 3.3 | 6.7 |
| | 17. Frequent coughing can be a symptom of asthma (T) | 82.1 | 1.8 | 16.1 |
| | 36. Asthma attacks often come on suddenly without any warning symptoms (F) | 13.3 | 80.0 | 6.7 |

# Appendix G

## Full Study Ethics Approval


**Office of Research Ethics**

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

**Use of Human Subjects - Ethics Approval Notice**

**Principal Investigator:** Dr. L. Swartzman
**Review Number:** 16869E **Review Level:** Expedited
**Review Date:** February 10, 2010 **Approved Local # of Participants:** 120
**Protocol Title:** The Additive and Interactive Effects of Patients' Asthma Knowledge, Beliefs and Treatment Preferences on Medication Choices
**Department and Institution:** Psychology, University of Western Ontario
**Sponsor:**
**Ethics Approval Date:** March 09, 2010 **Expiry Date:** September 30, 2011
**Documents Reviewed and Approved:** UWO Protocol, Letter of Information and Consent. Telephone Script.
**Documents Received for Information:**

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
FDA Ref. #: IRB 00000940

## Appendix H

## Letter of Information


LETTER OF INFORMATION

Project Title: The additive and interactive effects of patients' asthma knowledge, beliefs and treatment preferences on medication choices

Investigators: Dr. Leora Swartzman, Psychology, UWO

Ms. Naomi Gryfe, Psychology, UWO

Dr. Christopher Lisckai, St Joseph's Health Centre

**Purpose of the Study**

As an individual attending the asthma clinic, you are being invited to voluntarily participate in a research study looking at patients' views about asthma and what you feel is important for your treatment.

The purpose of this letter is to provide you with the information you require to make an informed decision to participate in this research.

**Procedures**

Approximately 120 patients will be approached to take part in this study. If you decide to participate you will be asked to sign the consent form and then complete:

1. Surveys while you wait to see your physician today. These surveys will take approximately 15 minutes to complete and will ask you about your experiences while having an asthma attack and some information about you.

2. Surveys after you see your physician today. These surveys will take approximately 25-30 minutes to complete. In these questionnaires, you will be asked about your thoughts about asthma, what you feel is important for your treatment, and the way in which you are currently using your medications (if any medications have been prescribed for you).

3. At home tonight, you will be asked to complete a 5 minute survey about your satisfaction with your appointment. You may complete these surveys online or on paper copies which will be provided to you. Should you choose to complete these

surveys on paper copies, you will also be provided with a postage paid envelope and asked to mail the surveys back to the investigators.

4. For one week after your appointment, you will be asked to record your symptoms and when you take your medications. Again, you will have the option of completing these surveys online or by hand. You must return this package by mail (postage will be paid) or e-mail.

5. Four weeks after your appointment, you will be contacted by phone or email (your preference) and asked to again record your symptoms and medication s for one week (online or on paper copies which will be mailed to you). You will also be asked a few questions about how you take your medications and your quality of life. You must return the package by mail (postage will be paid) or e-mail.

**Reimbursement**

You will be reimbursed $10.00 for completing the portion of the study at today's visit. You will also receive $20.00 for completing each of the week-long symptom diaries and surveys. In total, you will be paid $50.00 to compensate you for your time. If you withdraw from the study early, you will be reimbursed according to the portion of the study that you complete.

**Risks and Discomforts**

We do not believe this study poses any risk to your health or safety.

**Benefits**

This research project may lead to the development of improved clinical care for patients suffering from asthma. You may not benefit personally from participation in the study.

**Withdrawal**

Participation in this study is completely voluntary. You may refuse to participate, refuse to answer questions, or withdraw from the study at any time with no effect on your future care.

**Confidentiality**

Maintaining your confidentiality is of the upmost importance to us. Your physician will not see any of your answers and if the results of this study are published, no one will know you were a part of the study. Your names will be removed from all of your answer booklets, and the unidentifiable information will be stored in a locked cabinet at the University of Western Ontario.

Should you decide to complete your questionnaires online, all of your information will be password protected on a secure network through the University of Western Ontario. All of your personal information will be removed from your answers one they are received.

We will only release your records should representatives of the University of Western Ontario Health Sciences Research Ethics Board wish to contact you or require access to your study-related records to monitor the conduct of the research.

**Contact Person**

If you have any questions about the study procedure or content, please feel free to contact Ms. Naomi Gryfe.

If you have questions about your rights as a research participant or the conduct of the study you may contact Dr. David Hill, Scientific Director, Lawson Health Research Institute.

**Legal Rights**

You do not waive any of your legal rights by signing the consent form.

This letter is yours to keep.

## Appendix I

## Informed Consent



Consent to participate in the study entitled:

The Additive and Interactive Effects of Patients' Asthma Knowledge, Beliefs, and Treatment Preferences on Medication Choices

I, _____, have read the Letter of Information, had the nature of the study explained to me, and I agree to participate.

All questions have been answered to my satisfaction.

_____ _____

DATE SIGNATURE

_____

NAME OF PERSON OBTAINING CONSENT (please print)

_____

SIGNATURE OF PERSON OBTAINING CONSENT

## Appendix J: Medication Diary

Please complete the chart below **at the end of each day of the week**:

| **MEDICATION** | *Example* *Thursday, March 2, 2010* | **Day 1** Date: _____ _____ | **Day 2** Date: _____ _____ | **Day 3** Date:_____ _____ | **Day 4** Date:_____ _____ | **Day 5** Date:_____ _____ | **Day 6** Date:_____ _____ | **Day 7** Date:_____ _____ |
|---|---|---|---|---|---|---|---|---|
| **I took my preventer medication at:** | *9:00 am 3:00 pm* | | | | | | | |
| **I took a total of __ puffs of my rescue inhaler today** | *2* | | | | | | | |
| **I used my rescue inhaler at ____** | *1:00 pm 4:00 pm* | | | | | | | |

On day one, please record the number listed on your **preventer** inhaler. If you have more than one inhaler, please record the number on each inhaler:
Inhaler 1: _____ Inhaler 2:_____ Inhaler 3:_____ Inhaler 4:_____
At the end of the week, please record the number listed on your **preventer** inhaler. If you have more than one inhaler, please record the numbers on each of the inhalers.
Inhaler 1: _____ Inhaler 2: _____ Inhaler 3: _____ Inhaler 4:_____

**Appendix K**

**Demographic Information**

## ABOUT YOUR ASTHMA

1. Have you been diagnosed with asthma (please circle yes or no)?

| YES | NO |
|---|---|
| If YES:<br>1. At what age were you given an asthma diagnosis:<br>_____<br>2. In what year were you given an asthma diagnosis:<br>_____ | |

2. Is this your first visit to this asthma clinic (please circle yes or no)?

| YES | NO<br>If NO: Not including this visit, how many times have you been seen at this asthma clinic (please circle)? | | | |
|---|---|---|---|---|
| | 1 Time | 2 Times | 3 Times | More than 3 Times |

3. In the past year, how many times have you had to:

i. Go to see your family doctor for breathing problems? _____
ii. Go to the emergency room (ER) for breathing problems? _____

4. Have you been prescribed any medications to help control your asthma (by your family doctor, the ER, or a doctor at this clinic)? Please circle yes or no.

| YES<br>If YES: Please list the names of the medications:<br>_____<br>Are you currently taking these medications? YES NO | NO |
|---|---|

## ABOUT YOU

Sex (please circle): Male Female
Date of Birth: _____ (DD/MM/YYYY)

1. What is the highest grade of school that you have ever attended? Add one year for each additional year beyond grade 13 (For example, two years of college would be 15 years).
_____ Years

2. Which of the following best describes your current job status (please check one)?

☐Employed outside of the home (30 or more hours a week)
☐Employed outside the home, part time (less than 30 hours a week)
☐Retired
☐Unemployed
☐Homemaker
☐On disability (Is this related to your asthma? Yes No)
☐Working from home
☐Other, please specify: _____
☐Student

3. What certificates, diplomas or degrees have you obtained?

☐None
☐Bachelor Degree(s) (ex: B.A., B.Sc.)
☐Secondary/ High School Certificate
☐Master Degree(s)
☐Trade certificate or diploma
☐Professional Degree (Medicine, dentistry, law)
☐Community College
☐Doctorate Degree

4. Describe the range in which your annual household income falls (please check one):

☐Under $20,000
☐$81,000-$100,000
☐$21,000- $40,000
☐Over $100,000
☐$41,000-$60,000
☐I would prefer not to say
☐$61,000-$80,000

5. Your current relationship status is:

☐Legally married (not separated)
☐In a relationship, but not living together
☐Separated or divorced
☐Single
☐Living common law
☐Widowed

## Appendix L

### Percentage of Sample who Answered Knowledge Items Correctly and Incorrectly

| Category | Item | Percent Correct | Percent Incorrect | Percent Unsure |
|---|---|---|---|---|
| Pathophysiology | 19. Having swollen airways does not increase the risk of having an asthma attack | 71.9 | 6.5 | 21.6 |
| | 24. When someone's asthma attack is over it means that the asthma has gone away | 94.2 | 2.9 | 2.9 |
| | 11. During an asthma attack, the muscles around the airways tighten and the airways become narrow | 94.2 | .7 | 5.1 |
| | 2. Asthma is a disease that does not last for a long time | 91.4 | 2.2 | 6.5 |
| | 33. If a person does not have asthma by age 40, they will never get it | 80.6 | 1.4 | 18.0 |
| | 32. Untreated asthma can cause death | 78.4 | 1.4 | 20.1 |
| | 19. Having swollen airways does not increase the risk of having an asthma attack | 71.9 | 6.5 | 21.6 |
| | 1. People with asthma can have swollen and inflamed airways even when they feel well | 68.8 | 12.3 | 18.8 |
| | 5. It is possible for asthma to be worse without noticing a change in their breathing | 61.4 | 11.4 | 26.4 |

| Category | Item | Percent Correct | Percent Incorrect | Percent Unsure |
|---|---|---|---|---|
| | 7. Asthma can be cured | 57.9 | 14.3 | 27.1 |
| Medication | 21. People with asthma can usually help control their symptoms by taking the appropriate medications | 95.0 | 1.4 | 3.6 |
| | 28. People with asthma do not need to take their daily inhaled steroids if they feel well | 89.9 | 5.1 | 5.0 |
| | 10. People with asthma should wait until their symptoms are really bad before using a quick relief medication | 86.3 | 7.9 | 5.8 |
| | 18. A combination inhaler includes two types of medication to control asthma | 79.9 | 2.9 | 17.3 |
| | 3. Quick relief medications should be taken every day, even if people are feeling well | 71.9 | 18 | 10.1 |
| | 25. It is okay to take inhaled steroids only when people notice their symptoms getting worse | 71.2 | 17.3 | 11.2 |
| | 9. Inhaled steroids (controller) prevent asthma attacks | 65.2 | 18.1 | 16.7 |
| | 14. Taking an antibiotic, such as penicillin, will help most bad asthma attacks | 56.8 | 35.3 | 7.9 |

| Category | Item | Percent Correct | Percent Incorrect | Percent Unsure |
|---|---|---|---|---|
| | 20. The purpose of steroid medication inhalers is to stop an asthma attack when it occurs | 51.8 | 35.3 | 12.9 |
| | 15. People may not notice improvements in their breathing for 1-4 weeks after they start using inhaled steroids | 38.8 | 28.8 | 32.4 |
| | 26. Inhaled steroids will relieve an asthma attack within 20 minutes | 33.3 | 33.3 | 33.3 |
| | 13. A person with asthma can use a combination inhaler for quick relief, even if they do not use it everyday | 13.7 | 56.8 | 29.5 |
| Technique | 12. People with asthma should rinse and gargle after each use of their inhaled steroid | 97.8 | .7 | 1.4 |
| | 4. People with asthma should try to hold their breath for 8-10 seconds after each puff of their inhaler | 91.4 | 3.6 | 4.3 |
| | 27. People with asthma should wait about one minute between puffs of their quick relief medication | 61.9 | 21.6 | 16.5 |
| | 29. People with asthma breathe out partially, but not fully, just before taking their medication | 52.5 | 28.8 | 18.7 |

| Category | Item | Percent Correct | Percent Incorrect | Percent Unsure |
|---|---|---|---|---|
| Environmental Triggers | 6. Molds can trigger asthma symptoms in some people | 97.1 | 1.4 | 1.4 |
| | 23. People with asthma should avoid exercise | 95.7 | .7 | 3.6 |
| | 8. Being around others who smoke does not bother a person's asthma, as long as they don't smoke themselves | 94.2 | 2.2 | 3.6 |
| | 22. People can usually help control their symptoms by taking avoiding things that make their asthma worse | 93.5 | 5.0 | 1.4 |
| | 16. Cold air can make asthma symptoms worse | 91.4 | 3.6 | 5.0 |
| | 31. Keeping bedroom windows open at night will help prevent asthma attacks. | 56.1 | 10.8 | 33.1 |
| Symptoms | 30. Asthma may cause wheezing during exercise | 94.2 | 1.4 | 4.3 |
| | 34. Chest tightness is a common symptom of asthma | 90.6 | 2.2 | 7.2 |
| | 35. People with asthma get relief from their symptoms at night | 85.6 | 3.6 | 10.8 |
| | 17. Frequent coughing can be a symptom of asthma | 84.2 | 4.3 | 11.5 |

## Appendix M

## Summary of Hierarchical Regression Analysis with Patient Preferences Entered at Step One

| | Model | |
|---|---|---|
| Variable | 1 β | 2 β |
| Preferences | | |
| Long Term – Equal Group | **-.40**$^{***}$ | **-.25**$^{**}$ |
| Long Term – Side Effects | -.02 | .74 |
| Long Term to Efficacy | -.17 | -.16 |
| Pathophysiology Knowledge | | .07 |
| Beliefs | | |
| Timeline- Acute/Chronic | | .03 |
| Necessity of Medication | | **3.34**$^{***}$ |
| Concern of Medication | | -.78 |
| $R^2$ | .14 | .33 |
| $\Delta R^2$ | | .19 |
| $F$ | **5.44**$^{**}$ | **4.00**$^{***}$ |
| $\Delta F$ | | 3.10 |

$^{**}$ $p < .01$. $^{***}$ $p < .001$.

# Vita

## ACADEMIC BACKGROUND

**Doctoral Candidate, Clinical Psychology** **2007-Present**

*Department of Psychology, University of Western Ontario, London, ON, Canada*

Dissertation Title: The additive and interactive effects of patients' knowledge, beliefs, and values on asthma medication adherence.

**Master of Science, Clinical Psychology** **2007**

*Department of Psychology, University of Western Ontario, London, ON, Canada*

Master's Thesis Title: The impact of manipulated and non-manipulated expectations on placebo analgesia and nocebo responses in a sample of fibromyalgia patients.

**Honours Bachelor of Arts, Psychology (Summa Cum Laude)** **2005**

*Faculty of Arts, York University, Toronto, ON, Canada*

## AWARDS

**Canada Graduate Scholarship Doctoral Award (CGS)** **2008 - 2011**

*Canadian Institutes of Health Research (CIHR), Ottawa, ON, Canada*

**Accelerate Ontario Research Award** **2008**

*MITACS, Toronto, ON, Canada*

**Canada Graduate Scholarship Master's Award (CGS)** **2006 - 2007**

*Canadian Institutes of Health Research (CIHR), Ottawa, ON, Canada*

**York University Continuing Education Scholarship** **2001-2005**

*York University, Toronto, ON, Canada*

**York University Faculty Association Undergraduate Scholarship** **2003-2004**

*York University, Toronto, ON, Canada*

**York University Entrance Scholarship** **2001**

*York University, Toronto, ON, Canada*

## JOURNAL PUBLICATIONS

**Gryfe Saperia, N.J.,** & Swartzman, L.C. (2011). Openness to psychological explanations and treatments among people with fibromyalgia versus rheumatoid arthritis. *Psychology and Health*, Epub ahead of print, July 26. doi: 10.1080/08870446.2011.563852

## POSTER PRESENTATIONS

**Society of Medical Decision Making, Annual Meeting** **2011**

**Gryfe Saperia, N.**, Swartzman, L., & Lisckai, C. (2011). *Group clustering of DCE-elicited preferences predicts adherence to asthma preveter medication.*Chicago, Illinois.

**Canadian Psychological Association Annual Conference** **2011**

**Gryfe Saperia, N.**, Zhang, K.M., & Swartzman, L. (2011). *Sick with regret: How anticipated emotion influences the inclination to get the H1N1 shot.* Toronto, Canada.

**Society of Behavioral Medicine Conference** **2011**

Zhang, K.M., **Gryfe Saperia, N.,** & Swartzman, L.C. (2011). *Getting vaccinated against H1N1: The relative roles of perceived risk, anticipated regret and medical skepticism.* Washington, D.C.

**Society of Behavioral Medicine Conference** **2009**

**Gryfe Saperia, N.J.,** & Swartzman, L.C. (2009). *Reactions of implicit psychogenic accusations of illness among patients with fibromyalgia.* Montreal, Canada.

**Canadian Psychological Association Annual Conference** **2009**

**Gryfe Saperia, N.J**. & Swartzman, L. (2009). *The effects of pre-existing and in-session expectations on opioid analgesia in women with fibromyalgia: A pilot study.* Montreal, Canada.

**Canadian Psychological Association Annual Conference** **2007**

Chan, A.D.F., **Gryfe, N.J**., Herman, J., Moulin, D., Morley-Forster, P., & Swartzman, L. (2007). *The influence of the working alliance on enablement and satisfaction in chronic pain consultations.* Ottawa, Ontario.