

**THE INFLUENCE OF GENDER ON SELF-REPORTING OF RESPIRATORY  
SYMPTOMS**

**By**

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## **ABSTRACT**

The American Thoracic Society Questionnaire (ATSQ), an epidemiological questionnaire that is widely used in North America to gather self-reported respiratory symptom data, was recently revised and released for further validity testing. Reviews of gender and respiratory disease have revealed potential gender differences in self-reported respiratory symptoms, specifically phlegm and dyspnea. The purpose of this study was to describe the cognitive processes that men and women engaged in when responding to ATSQ questions and to compare these processes for potential differences between men and women and to suggest improvements to the ATSQ based on this analysis. This study generated an emergent conceptual model based on semi-structured individual interviews with 20 male and 20 female Coastal Marine Transportation Workers. The findings of the study suggest that respondents interpreted ATSQ questions, reflexively noticed ATSQ symptoms, and integrated their interpretations and experiences to formulate a response. Respondents who clearly defined themselves as either healthy or unhealthy with regards to ATSQ symptoms easily formulated their responses. Conversely, respondents who experienced tension between their interpretations of questions, reflexive noticing of symptoms, and self-identity as healthy or unhealthy, struggled to provide accurate responses. While the response processes were similar for men and women, gendered work environments and the masculine nature of expectorating phlegm emerged as factors that differentially influenced men's and women's responses. It is recommended that revisions be made to the ATSQ to help mitigate tensions experienced by some respondents when formulating their symptom responses.

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## **CHAPTER ONE: INTRODUCTION**

In the past fifty years, the demographics of chronic obstructive pulmonary disease (COPD) and asthma<sup>1</sup> have shifted dramatically. Traditionally thought of as a disease affecting older males, reported rates of COPD have increased considerably amongst women, particularly between 35 and 75 years of age [1]. In Canada, data from the 1998/99 National Population Health Survey (NPHS) indicated that 3.2% of the Canadian population had received a diagnosis of COPD; 2.8% of males (211,900 males) and 3.6% of females (286,600 females) [1]. In addition, COPD mortality rates among women have been fast approaching and are expected to surpass those of men [1]. During the 2000/01 year, 6.9% of males compared to 9.9% of females self-reported a diagnosis of asthma [2]. As well, between 1994/95 and 1998/99 waves of the NPHS, the prevalence of physician-diagnosed asthma increased by 37% and 58% among women aged 20-44 and 45-64 respectively and by 33% among men aged 20-44 [1]. In light of these gendered trends, researchers have increasingly begun to focus on the impact of sex and gender on obstructive lung disease.

One method of obtaining prevalence estimates for obstructive lung disease is through self-report surveys of respiratory symptoms that characterize both asthma and COPD (i.e., cough, phlegm, wheeze, and dyspnea). However, emerging evidence suggests that there are potential gender differences in the self-reporting of these symptoms [3], which may have an impact on both prevalence estimates and disease

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<sup>1</sup> Throughout this thesis, Obstructive Lung Disease will be used as a common term to refer to both COPD (an irreversible inflammation and obstruction of the airways, typically characterized by a decrease in quality of life and eventually, death) and asthma (a chronic condition, usually characterized by acute but generally reversible attacks of breathlessness, also associated with inflammation and narrowing of the airways).



diagnosis. Hence, researchers have begun to theorize about potential explanations for observed differences between men and women.

The influence of gender on the reporting of symptoms (as measures of overall morbidity) has a long history in the social and health sciences [4]. In these bodies of research, gender has come to be conceptualized as a complex variable, influenced by many aspects of one's life and interactions across those various aspects [5]. For example, studies have shown that socioeconomic status, social roles, and expectations of masculinity and femininity, all affect men's and women's experiences with health and illness, and hence symptom reporting [6]. This body of research has only begun to be integrated into research on men's and women's patterns of reporting of respiratory symptoms [3].

Drawing on data related to symptom reporting, as gathered through the American Thoracic Society Epidemiological Questionnaire (ATSQ), the aim of the current study is to illustrate the complex nature of the mechanisms through which gender affects interpretations of and responses to self-report respiratory symptom questions. The ATSQ was first developed in 1978 [7], adapted in part from the British Medical Research Council Questionnaire. The ATSQ includes six domains and is widely used in population-based and occupational respiratory health studies as a measure of respiratory morbidity. The respiratory symptom domain on the ATSQ includes a total of 71 questions, although skip patterns allow some respondents to skip redundant questions.

Five symptom categories of obstructive lung disease are investigated through this questionnaire: (1) cough, (2) phlegm, (3) episodes of cough with phlegm, (4) wheeze, and

(5) shortness of breath (see Appendix B). These symptoms are often used as markers of asthma and COPD.

In 2004-2005, the ATSQ underwent revisions and the findings of the current thesis will inform its ongoing validation. Additionally, research on gendered health experiences and outcomes are re-emerging areas of interest, where theoretical advances are being made in the conceptualization of the mechanisms through which gender affects health and illness [8]. Research on the effects of gender on self-reported respiratory symptoms is timely, as sex and gender differences in exposures, physiology, and diagnoses, in combination with rising rates of respiratory disease among women, have begun to draw research attention in Canada and internationally.

#### **I. Purpose of the Current Study**

The purpose of the current study is to investigate the influence of gender on men's and women's self-reports of respiratory symptoms on the ATSQ. During face-to-face, semi-structured interviews, a sample of 20 men and 20 women provided detailed descriptions of their perspectives on what affected symptom reporting on the ATSQ. Study participants were invited to describe the cognitive processes that they engaged in to formulate their interpretations of and responses to the ATSQ items related to cough, phlegm, episodes of cough with phlegm, wheeze, and shortness of breath. The study was guided by the following research questions:

1. How do men and women interpret the ATSQ respiratory symptom questions?
2. How do men and women describe the cognitive processes that they engage in when answering the ATSQ questions?

3. How do gender-related psycho-social factors affect men's and women's responses to the ATSQ questions?

## **II. Study Setting**

Interviews were conducted with BC Coastal Marine Transportation Workers in Greater Vancouver and Vancouver Island, during the fall of 2005. At the time of the interviews, this population was participating in the fifth wave of an occupational health study and was completing both the revised and original versions of the ATSQ (see Appendix B).

## **CHAPTER 2: REVIEW OF THE LITERATURE**

The ATSQ is widely used to collect symptom data in occupational, environmental and population-based epidemiological studies; however, recent evidence suggests that there are gender differences in the perception and/or reporting of respiratory symptoms [3]. While several studies have noted differences between the symptom-reporting patterns of women and men, limited research has addressed the aetiology of these differences [3, 9-11]. Observed gender differences in reporting patterns, have at times been attributed to differences in men's and women's gendered socializations (e.g., norms related to femininities and masculinities) [3, 12]. This review of the literature examines the empirical and theoretical support for this potential explanation, drawing primarily on research pertaining to gender as a social construct, survey methodology, and respiratory epidemiology to examine the potential effect of gender on self-reports of respiratory symptoms.

### **I. Defining Sex and Gender**

"Sex" and "gender" are the terms used to distinguish between males and females, as well as men and women, within the health research literature [8, 13-19]. The distinction between sex and gender was first popularized by Ann Oakley in 1972 [17], who defined the term "sex" as the biological component of being a male or female; the physical (e.g., differences in lung capacity and airway size), genetic (e.g., possible differences in susceptibility to tobacco smoke), and hormonal characteristics (e.g., influence of cyclical hormonal variations on the hyperresponsiveness of airways of the lungs). In contrast, Oakley defined "gender" as the product of social constructions of femininity and masculinity, whereby, "to be a man or woman, a boy or girl, is as much a

function of dress, gesture, occupation, social network and personality, as it is of possessing a particular set of genitals” [17, p.158]. While the basic tenets of Oakley’s definitions of sex and gender have been adopted in gender and health research, many progressions in the definition of gender have been made since the 1970s [5, 15]. Furthermore, while distinguishing between the terms “sex” and “gender” may be useful conceptually, it is not always feasible empirically. Therefore, although the current study has focused on the effects of gender (as a social construct) on respiratory symptom reporting, it is acknowledged that the effects of gender on symptom reporting are also likely influenced by sex.

The definition of gender that will be adopted for use in the current thesis is that of an “institutionalized system of social practices” [5], whereby men and women come to perceive themselves and others as gendered beings<sup>2</sup> through their interactions with:

1. Macro-level institutions (e.g., the nuclear family, the structure of employment, health and social policies, cultural belief systems of gender role expectations and other factors that have the potential to create gender inequalities in health) [4, 20, 21]; and
2. Social actors (e.g., social expectations related to masculinities and femininities that are manifested through interactions amongst people and between people and institutions) [5, 16, 22, 23].

Through these interactions, individuals produce and (re)produce understandings of who they are as gendered beings (and how they are perceived by others), as well as the opportunities and disadvantages that their gendered identities afford them through the

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<sup>2</sup> This follows a constructionist perspective developed from the sociological theory of symbolic interactionism. Here individuals actively create/re-create the society they form a part of through everyday interactions. Gender is one aspect of society re-created through the everyday interactions of its members.

social positions that they occupy. As succinctly described by Courtney [22, p.1387], “gender does not reside in the person, but rather in social transactions defined as gendered.” A person constructs themselves as a “gendered being” (and is constructed by others) through understandings of cultural expectations of masculinities and femininities. Gendered construction of self and others may take on different forms depending on the nature of the interactions, but perceptions of gender often align with hegemonic views of masculine and feminine roles and behaviours [22]. In this way “it is gender as an ideological and institutional structure that determines how men’s and women’s experiences in similar contexts (for example, in the labour market, or in the family) are differentiated” [24, p.292].

## **II. Perceiving and Reporting Symptoms**

Gender has been shown to significantly influence self-reporting of symptoms [3, 13, 22, 23] and there is emerging evidence of gender differences in self-reports of specific respiratory symptoms [3, 12, 25]. The current study provides a unique opportunity to examine gender influences (conceptualised as a function of both institutions and social relations) on responses to ATSQ questions that solicit self-reported respiratory symptoms [22]. Self-reporting of symptoms, while resulting from the detection of somatic changes in the body, is also a socially-constructed behaviour, influenced by socio-structural factors, as well as individual experiences during social interactions [26-28].

Several researchers have developed models to help elucidate the way that individuals come to perceive and interpret somatic bodily changes. In 1980<sup>3</sup>, Leventhal

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<sup>3</sup> In 1986, Leventhal adapted the Common Sense Model to also include a more detailed biopsychosocial representation of symptom processing, as a component of chronic illness.

[27] published the Common Sense Representation of Illness Model, which delineates how patients diagnosed with chronic disease come to label and interpret their disease experience, while in 1994 a group of researchers from UCSF developed an Intrapersonal Model of Symptom Perception for the purposes of symptom management [see 29]. However, neither of these models provide descriptions of the reasoning that occurs regarding decisions to report (or not) a specific symptom.

Teel et al. [29] developed the Symptom Interpretation Model as a tool to help health care providers to understand symptoms from the patient's perspective. The Symptom Interpretation Model includes three stages: (1) an internal or external input creates a disturbance with sufficient impact so as to create awareness; (2) the individual interprets the sensations created by the somatic disturbance; and (3) the individual makes a decision regarding whether they need to seek medical attention. While the three models discussed above provide some insights into the process of symptom reporting, they were developed to conceptualize the processes that *patient* populations engage in when perceiving symptoms and deciding to seek care for symptoms; the ATSQ, alternatively, is often used in *population-based* studies.

The most detailed, generalized symptom perception model was developed by Gijsber van Wijk et al. [30] in 1997. Drawing on Gijsbers van Wijk et al.'s [30] Symptom Perception Model, and using the example of respiratory symptoms, perception and self-reporting of symptoms was conceptualized in the following way:

Firstly, the input of somatic information occurs (e.g., airway inflammation). This information is perceived by the individual, if their attentional processes focus on internal bodily cues (e.g., a quiet moment at the end of the day, void of external competition for

attention). Once this occurs, the somatic sensations associated with a specific disease may be detected (e.g., dyspnea). These sensations are then attributed to somatic or psychological causes (e.g., a decision is made as to whether the dyspnea is caused by a physical disease process or simply stress or lack of conditioning). In this stage, “sensations are attributed to symptoms of somatic or emotional distress, or to a normal response to environmental conditions, largely depend[ent] on the subjective meaning of these sensations; such interpretation involves multiple aspects and is influenced by personality characteristics as well as by gender-role expectations” [31, p.4]. The final stage of the model results in the individual displaying and reporting somatic or psychological distress and illness behaviour (e.g., a decision to seek or not seek care from a health professional).

While respondents may draw on their previous perception of symptoms to formulate responses to symptom questionnaires, the process that they engage in during the research interview (or even during self-administered surveys) differs from symptom perception in daily life and consequent decisions to report symptoms to a health care professional. Most notably, survey questions often stimulate respondents to consider events (such as symptoms) that they may not have considered previously [32]. Research on the Cognitive Aspects of Survey Methodology (CASM) has focused extensively on the cognitive processes that respondents engage in when responding to self-administered and/or interviewer-administered questionnaires, as well as how the design of the questions and the context of the interview influence respondents’ interpretations of and responses to questions [33-40].



## **Cognitive Aspects of Survey Methodology**

Several authors have developed models or “cognitive steps” to explain the cognitive processes undertaken in responding to survey questions [33, 36, 39]. Many of the models delineate the response formulation process as including the following: interpreting the question, re-calling the event (e.g., the symptom), making judgments or interpretations of the event, and reporting. While the models delineate a linear progression through the various stages, researchers have acknowledged that there is likely interplay between the stages [33, 37]. Many authors have also found that some people more thoroughly engage in the cognitive processes outlined above (referred to as optimizing), while others only superficially engage in these cognitive processes (referred to as satisficing)<sup>4</sup> [41].

Variations to this general model also have been proposed. Groves et al. [33] have suggested that an initial process of encoding must happen before respondents can adequately recall the symptom in question (similar to symptom perception). Once an individual has noticed a symptom, they form a memory of the experience, defined as encoding. The process of encoding consequently influences a respondents’ ability to recall the symptom event. Schwarz [37] has shown that serious, rare events are more likely to be encoded than more minor, frequent events. Knauper and Turner [36] also have found that respondents often engage in an affectively-based reaction to the question, depending on the prior encoding processes that they have engaged in. If a respondent has engaged in previous encoding, as well as formed a prior judgment about the importance of the encoded information, then an affective response is more likely to lead directly to a

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<sup>4</sup> A more thorough discussion of the concepts of satisficing and optimizing can be found in the literature on cognitive economy.

judgment and response (by skipping the recall process) [32]. For example, respondents who have previously noted that they are in excellent health have been shown to truncate the recall and judgment processes and report their health accordingly [36].

The interpretation stage of survey response models, has been shown to be influenced not only by the wording used, but also by the response format, prior questions and the respondents' understanding of the overall goal of the research project, referred to as context effects [35-37, 42]. Increasingly, researchers have come to see respondents' interpretations of questions within the context of conversational processes, whereby respondents are viewed as cooperative communicators who seek to provide the information that they believe the researcher is requesting [36]. Schober [43] has proposed that it is only by considering respondents to be "engaged in interactive processes, not just individual cognitive processes" that we can come to understand how people make sense of questions. In everyday conversation, questions are designed specifically for the individual respondent and the respondent has the opportunity to interact with the questioner in order to interpret the pragmatic meaning of the question being posed [43]. In research settings, questions are designed for a prototypical person (referred to as audience design) and standardized interview protocols limit the conversational interactions between the interviewer and the respondent [34, 43]. Therefore, respondents attempt to interpret questions based on how they think an "average" respondent would interpret the question.

Schober [43] has also argued that because interactions with interviewers are restricted by standardized interview protocol, respondents' ability to correctly understand and interpret questions that are asked of them, is further limited (i.e., the respondent is

unable to assess a common understanding of the question between him/herself and the researcher, a process referred to as grounding)<sup>5</sup>. Given the lack of interaction between the interviewer and respondent, the respondent has been shown to rely heavily on formal aspects of the survey questions to inform the cognitive processes they engage in to select their response [43, 44]. For example, filter questions, and resulting skip patterns, have been shown to influence respondents' interpretations of the intended meaning of questions [35]. Given this reliance on question wording and design, it is essential that survey questions are relevant and well designed. Mallinson [42] has found that respondent cooperation is hindered by poorly conceived or seemingly irrelevant questions.

According to the CASM literature, in the second stage of the reporting process respondents engage in recalling events; to do this they look to retrieval cues [33]. These cues help trigger the recall of information needed to make a reporting decision about the event in question. It has been shown that individuals do not necessarily review all information related to an event, but rather, they stop the process of recall once they feel they have accessed enough information to form a judgment [37]. Knauper and Turner [36] find that retrieval cues for health related questions are based on semantic knowledge (e.g., health behaviour and knowledge), episodic knowledge (e.g., episodes of complaints), and information about change (e.g., changes across the life-span). Event recall is also influenced by the previously mentioned process of encoding [33].

During the judgment phase of cognition models, information from the previous stages is thought to be integrated and supplemented to form a final reporting decision [33,

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<sup>5</sup> Using the talk-aloud technique, Mallinson [42] found that, given the interactive nature of the survey interview, interviewer deviation from standardization procedures was often necessary to prevent alienating respondents.

36]. For example, Knauper and Turner [36] have found that in the judgment stage respondents engage in social comparisons with people of a similar age. Through this process of comparing, respondents form a judgment about the extent to which they recall experiencing an event, compared to others their same age. Here again, the respondent may draw on their understanding of the research goal in order to determine if his/her recall matches the objective of the study [33].

Finally, cognitive models have shown that in the reporting phase, respondents choose the particular response option that they feel best suits their experience with and judgment of the event in question [33, 36, 39]. In this stage, the respondent has to communicate their response to the interviewer and may choose to edit his/her response due to social desirability and self-presentation [37]. While it has been suggested that the response format may lead respondents to view certain response options as deviations from the average (e.g., the “bookends” on a response scale), and hence less socially desirable, to date, there is little empirical evidence to support or refute this theory [see 37].

### **III. The Effects of Gender-Related Psychosocial Factors on Symptom Perception and Reporting**

To date, limited research has been conducted specifically on the effects of gender on respiratory-symptom reporting; however, there has been some important work that helps explain gender differences in self-reported morbidity in other illness (e.g., irritable bowel syndrome and osteoarthritis) [45, 46], mental health (e.g., depression) [47] and self-rated health status (e.g., general measures of morbidity) [13]. However, explanations for observed gender differences tend to be theoretical in nature (but often lack empirical

support). Most previous research has focused on the *experience and perception* of symptoms (or illness as measured by self-reports of symptoms), but very little research has been conducted on potential gender differences in *reporting* on research surveys.

During the 1970s and 80s, social science and epidemiological studies began providing evidence of gender differences in self-reported health using measures of morbidity, such as physical and mental health symptoms [4, 48]. Specifically, evidence suggested an excess self-reported morbidity amongst females [4, 13, 48, 49].

Subsequently, this early work stimulated debate about possible explanations for this gendered trend, although additional research (e.g., that specifically focused on osteoarthritis) called into question the heretofore reported excess of morbidity amongst women [19, 23, 45, 50-52]. Questions also began to emerge regarding the medicalization<sup>6</sup> and psychologizing<sup>7</sup> of women's experiences of health and illness [53].

New research helped to identify some of the empirical and theoretical limitations involved in isolating the concepts of "health" and "ill health" from the social contexts within which both men and women experience health-related symptoms<sup>8</sup> [24].

Coincidentally, new questions are emerging from a growing body of literature on the potentially complex interactions between sex and gender (as well as emerging work on more nuanced conceptualizations of sex and gender), which may help researchers to better understand the aetiology of observed gender differences in symptom reporting and ultimately health [14, 15, 46, 54, 55]. Nevertheless, within this diverse body of literature

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<sup>6</sup> Medicalization reduces women's problems to physical complaints needing medical intervention and/or medical research.

<sup>7</sup> Psychologizing refers to the attribution of psychological causes to physical complaints (often described as medically unexplained symptoms).

<sup>8</sup> Moreover, much of the research on "gender and health" focused primarily on women's health, while men's health remained relatively unexamined from a gendered perspective.

on gender differences in health and health outcomes, several explanations for observed gender differences in reported symptoms have been put forward and are summarized below.

### **Socio-economic explanations**

A vast body of literature has shown consistent links between lower socio-economic standing and ill health [56]. Typically, women have been expected to take a more active role in unpaid, domestic duties, such as childcare, housecleaning, and meal preparation [6]. At the structural level, women are thus relegated to economically marginalized positions (e.g., dependent on male spouse's income, predominance of single-mother households, disproportionate representation of women in part-time, insecure employment that can accommodate domestic responsibilities) [56, 57]. The higher prevalence of women living in poverty is one factor that has been thought to lead to greater experiences of morbidity among women [24].

### **Role-based explanations**

Men's and women's role obligations have also been posited to lead to differences in emotional or stress related exposures, which in turn are thought to lead to higher rates of reported morbidity among women [24, 30, 58], especially with regard to symptoms associated with distress (e.g., mental health symptoms and possibly non-specific symptoms including dyspnea). For example, jobs available to women are often part-time, less secure and provide less autonomy and control than those available to men (referred to as precarious employment) [6]. These job characteristics, in addition to enhancing the overall economic marginalization of women, also result in more stressful working conditions for women [59].

Additionally, research has begun to acknowledge that the workplace is a venue for further constructions of gender identities [6]. For example, gendered performances such as, “male and female codes of dress, sexual harassment, or the predominance of a masculine culture of sexuality,” [6, p.8] have all been found to influence men’s and women’s experiences within their workplace. As a result, women in the workforce may experience greater job related dissatisfaction and resulting stress [56, 59], particularly for women who maintain domestic role obligations, as the jobs available to them are more likely be part-time and less-secure due to the need to accommodate family responsibilities [6, 57, 60]. Thus, while a negative correlation between employment and morbidity has been consistently observed, the health benefits of employment have been shown to be less for women than for men and for employed mothers as compared to women without children [24]. Women also often have multiple role obligations (e.g., domestic and labour force responsibilities—“the second shift” phenomenon<sup>9</sup>), which have been proposed to lead to higher levels of stress [6]. This may be especially true for mothers who are primarily responsible for childcare and who experience financial insecurity [24]. Interestingly, Denton et al. [56] have found that stress has a greater negative impact on women’s health, than on men’s.

Conversely, other authors have suggested that having multiple role occupancies actually allows individuals to diffuse frustrations with a specific role by switching between roles in times of discontent [6]. Providing support to this hypothesis, Hibbard and Pope [61] measured variations in levels of responsibility through an index of employment and child obligations. They found that females experiencing both

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<sup>9</sup> Women returning to their households after spending their days in the paid workforce are still expected to take responsibility for domestic activities such as childcare, meal preparation and household cleaning.

employment and child obligations report fewer symptoms than those without this double role “obligation” (or opportunity). Gijbbers Van Wijk et al., [30, 58] have proposed an alternative explanation for findings such as Hibbard and Pope’s. They have suggested that women, who “only” carry domestic role obligations, find themselves in “underload external situations” (i.e., bored housewife). This lack of external information leads to a greater focus on internal bodily symptoms and in turn to a greater detection of somatic changes. Gijbbers Van Wijk et al.’s hypothesis, however, is based on a value judgement regarding the simplicity of domestic role responsibilities. Furthermore, Gijbbers Van Wijk and Kolk [30] have found that men and women rely on different cues in the detection of symptoms. Men focus more on physical bodily cues, while women rely more on external, situational cues. In short, it is unclear how, and if, women’s social roles contribute to higher rates of self-reported morbidity. In fact, there is now a general acknowledgment amongst gender and health researchers, that neither gender, nor social roles, are homogenous variables and that more attention should be devoted to the specific conditions under which social roles are beneficial to men’s and women’s health [6].

### **Hegemonic Forms of Masculinity and Femininity as Explanation**

Socializations of femininity and masculinity have also been proposed to account for gender differences in men’s and women’s perceptions of health and their health behaviours [13]. It has been argued that because health has, traditionally, been described as a “masculine concept” (where women are held to a “less adult” standard of health than men) it is therefore less stigmatizing for women to report symptoms of illness [4, 23, 48]. The basic premise of these arguments is that by refusing to admit to illness, men are re-establishing their masculinity and their bodies as more powerful and efficient than



women's bodies [22], constructing their masculine identities through a rejection of feminine symptom reporting behaviour. Through stoicism, they re-enforce their physical power as men [31]. Equally, researchers have proposed that it is acceptable for women be seen as ill [48]. Therefore, it has been suggested that it is more acceptable for women to focus internally and look for bodily symptoms, to report symptoms to others, or to seek health care in response to their symptoms [23, 30, 48]. Studies have shown that higher scores on a masculinity index<sup>10</sup> are inversely correlated with self-reported morbidity and number of symptoms [13, 16, 54, 62]. While Annandale and Hunt [13] have interpreted the correlation between masculinity and low levels of self-reported morbidity as evidence of the positive effect of stereotypical masculinity on health, it is possible that this correlation in fact evidences a suppression of reports of ill health [22, 31].

Other research has suggested that men and women differentially conceptualize what it means to be healthy (calling into question the assertions that imply that men are "not allowed" to be sick) [23]. Within this body of work, men are viewed to be more reticent to report *specific* symptoms (especially those symptoms deemed to reveal weakness or that are seen to be stereotypically feminine), rather than simply less likely to report any symptom [19, 45, 48]. As well, when defining health, women have been found to have included criteria such as emotional and social well-being whereas men focused on a lack of physical ailments [23, 31, 63]. Similarly, several authors have proposed that women may be more aware of and more attentive to weak or diffuse bodily stimuli and also differ in how readily they conclude that diffuse or mild sensations are because of ill-health [48, 64]. For example, Mechanic [48] found that the largest gender differences in

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<sup>10</sup> While this observed correlation is true for both men and women, men are still more likely to rate themselves as more masculine than women are.

reporting are found for symptoms of subjective distress and psycho-physiological symptoms.

Research on pain also has illustrated how gender differences in observed symptoms may result from differences in men's and women's concepts of health. Koutanji et al. [65] have suggested that social expectations are more supportive of women reporting pain and therefore, women have learnt that it is acceptable for them to be aware of their own and others' pain. Wise et al. [66] used the Gender Role Expectations of Pain (GREP) questionnaire in a young adult university population (n=148) and found that women reported a significantly greater willingness to report pain when asked to compare themselves to the "typical man" and men reported a lower willingness to report pain when asked to compare themselves to the "typical woman." The authors also found that men were more hesitant to disclose pain to others and were more likely to experience feelings of embarrassment at having to admit to pain. Gendered socialization is thought to be responsible for these findings.

Conversely, Davis [45] in her analysis of 1971-5 National Health and Nutrition Examination Survey (NHANES) data found that controlling for objective osteoarthritis disease markers altered the relationship between gender and the reporting of pain. Although initially more women reported the symptom of chronic pain, once disease status was controlled for, men became more likely to report this pain than women, per degree of objective impairment. Therefore, it appears that once pain was associated with a specific disease, men were equally, or even more likely to report pain. Other authors have also provided support for the finding that once a diagnosed disease is present, men and women are equally likely or men become more likely to report related symptoms [19, 30].

Gendered socialization has also been found to lead to differences between men and women in their health seeking behaviour. Women have been found to be consistently more likely to consult a general practitioner [31]. As a result, it has been hypothesized that women may be more aware of medical terminology and have a broader medical knowledge [45, 64]. This knowledge, in turn, has been proposed to enforce women's awareness of internal symptoms and readiness to report symptoms [48]. In support of this hypothesis, Mechanic [48] found that persons who had taken some form of action regarding a symptom were more likely to re-call that symptom.

Men's and women's definitions of health may also affect the *ways* in which they seek care, rather than simply *whether* they seek care. For example, Verbrugge suggested that men may be more reluctant to seek care for symptoms for which they do not know the cause [4]. While physical symptoms are usually the determining factor in decisions to seek health care, psychosocial problems and distress contribute to women's decisions to seek care more frequently than men's [67]. Men seeking care may be more interested in obtaining a label for their symptoms, whereas women are more likely to be seeking reassurance from their doctor [31].

Studies have also revealed that interactions with healthcare providers can further confirm the ethic of health as masculine, especially regarding affective symptoms. For example, Nathanson [23] reviewed several studies which found that healthcare providers more strongly rejected a diagnosis of mental illness when patient scenarios were presented using male patients than female patients. Based on interviews with men experiencing infertility, Moynihan [16] recounted discussions of clinicians' use of language as reinforcing masculine ideologies of control over their bodies (e.g., referring

to infertility as “shooting blanks”). She discussed these patient physician interactions as having reinforced a dualism between mind and body and an estrangement from somatic experiences.

The majority of the literature discussed thus far pertained to the perception of symptoms in daily life and the reporting of symptoms in health consultations. There is little research on the effects of gender on symptom reporting within a research setting [68] and the few studies that did include gender did not find significant differences in reporting processes between men and women. Some studies have found that gender differences are greater for questions regarding retrospective recall of symptoms, as compared to health diary studies which use current symptoms [30]. However, other research has found that gender differences persist irrespective of the timeframe. This review of the literature did not uncover any research on how cognitive processes involved in survey response might differ for men versus women.

#### **IV. Self-Reporting of Respiratory Symptoms**

Self-reports of symptoms of obstructive lung disease (cough, phlegm, cough with phlegm, wheeze and dyspnea) have been shown to differ for men and women. The most consistently reported gender difference is a higher rate of reporting of dyspnea among women [3, 9-12, 25, 69-74]. Conversely, several studies have noted a higher rate of reporting of phlegm (and cough with phlegm) among men [3, 9, 12, 25, 70, 72, 75, 76], although a smaller number of other studies record the opposite trend [10, 11, 71, 77, 78]. No clear gendered trends have been observed for the symptoms of cough or wheeze [3, 9, 12] although it appears that cough is more common among women in patient populations [79, 80]. It has also been found that women tend to report more *severe* asthma related

symptoms (wheeze/dyspnea) than men [81]. While gender differences in symptom reporting have been noted in sex-stratified, epidemiological studies, there is little understanding of the gender-related mechanisms that contribute to these differences.

### **Effects of Gender-Related, Psycho-Social Factors on Respiratory Symptom Reporting**

In 1996, Kauffman and Becklake [3, 12, 25] published the first of three comprehensive reviews on the influence of sex and gender on respiratory health. In these publications, they reviewed biological, environmental and sociocultural factors that have been proposed to lead to differences in the ways that men and women experience respiratory illness. Their reviews highlight the complexity of the study of sex and gender in the area of respiratory health and illness, exemplified in their analysis of self-reporting of respiratory symptoms in epidemiological questionnaires. Using self-report data from the PAARC<sup>11</sup> survey, Kauffmann and Becklake [3, 12, 25] found that, after matching for quintiles of FEV<sub>1</sub> (forced expiratory volume in one second) and controlling for potential exposures, self-reported rates of dyspnea remained consistently higher for women than for men. Although this finding indicates that gender differences in self-reports of dyspnea existed above and beyond levels of obstruction, the reason for this difference remains unclear.

Several hypotheses have been proposed to explain the potentially higher rates of self-reported dyspnea among women. While there is some support for biological hypotheses (e.g., research conducted on sex differences in inspiratory muscle strength

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<sup>11</sup> The "Pollution Atmospherique et Affections Respiratoires Chroniques" (PAARC) survey was completed by 20,000 men and women in seven cities of France to examine the potential relationship between air pollution on respiratory disease.

and secondary sex characteristics) [3, 82], Kauffmann and Becklake [3, 12, 25] also hypothesize that in Western cultures where athleticism and stoicism are highly valued masculine characteristics, men may feel that experiencing and reporting the symptom of dyspnea is indicative of weakness and hence diminishes their masculinity. Although this theory has not been tested in empirical research within the field of respiratory health, there is evidence from research on gender and sport to suggest that athleticism contributes to men's definitions of their masculinity [83, 84]. In addition, the symptom of dyspnea<sup>12</sup> has been shown to encompass a multitude of descriptors and sensations such as: chest tightness, increased effort, inability to take a deep enough breath [85], difficulty breathing, air hunger, and many more [86, 87]. As well, dyspnea is the third most common complaint seen by health professionals and is not solely indicative of respiratory illness [86]. Given the non-specific, more emotive nature of dyspnea, it could be one such symptom where masculinities are maintained by denying experiences of breathlessness (see section three of this chapter).

Furthermore, while theories on stress have not been well integrated into the literature on gender and respiratory symptom reporting, research from other areas of health and illness indicates that women's social roles may produce higher rates of stress (see section three of this chapter). Stress, in turn, may have a greater influence on the perception of the symptom of dyspnea, as compared to perceptions related to other respiratory symptoms, such as phlegm. Similarly, women have been thought to experience a higher rate of depression than men and Martinex-Moragon and colleagues [88] have suggested that the correlation between depression and dyspnea could account

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<sup>12</sup> The American Thoracic Society defines dyspnea as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity"

for the observed higher reporting of dyspnea among women. However, given that Martinex-Moragon et al.'s study design is cross-sectional, causality could not be established. Lindberg et al. [70], in their ten year study of COPD incidence in a symptomatic cohort, found that dyspnea is only predictive of COPD in men (OR = 5.27). In addition, Knuiman et al. [89] found that while dyspnea was equally predictive of all cause mortality in men and women, it was only significantly predictive of respiratory mortality in men. This could indicate that while women are more apt to perceive and/or report dyspnea, the perception of this symptom in women is a less specific indicator of global health (i.e., not necessarily indicative of obstructive lung disease).

Again using data from the French PAARC survey, Kauffman and Becklake [3, 12, 25], found that men were three times more likely to answer affirmatively to the question, "Do you usually bring up phlegm?" However, when asked about *swallowed* phlegm, men were only twice as likely as women, to answer affirmatively. The authors attributed this to cultural ascriptions of desirable feminine behaviour which deter women from reporting phlegm, particularly expectorated phlegm. Lindberg et al. [70], in their ten year study of COPD incidence in a symptomatic cohort, find that the symptoms of cough, phlegm, and cough with phlegm, are only predictive of COPD in women (OR = 3.60, 2.97, and 2.93 respectively), providing additional evidence of a potential gender difference in reporting.

Many studies have shown the impact of smoking on the development of obstructive lung disease and have proposed that increased rates of smoking among women are responsible for the corresponding increase in rates of COPD among women [3, 18, 90]. Additional studies have shown that women may in fact be more susceptible to the negative affects of tobacco smoke [3, 18, 90, 91]. Camp, Dimich-Ward and Kennedy

[92] have also noted that occupational exposures vary greatly between men and women and to date, we know comparatively little regarding women's occupational exposures, as compared to men's. However, Kauffmann and Becklake [3, 12] have shown that gender differences in the reporting of dyspnea remain, and in fact increase, after controlling for exposure status. Potentially, men and women could hold differing representations of the meanings of exposure on their health and this could in turn influence their readiness to report certain symptoms. This review of the literature did not uncover any studies that explored how respondents assessed their exposure status and the potential influence of this assessment on their perceptions and reporting of symptoms.

A recent Canadian study by Chapman, Tashkin and Pye [93] illustrated a gender bias in the diagnoses of COPD and asthma. Given the same hypothetical scenarios for a man versus a woman, physicians were more likely to diagnose the woman as having asthma and the man as having COPD. Cydulka et al. [81] also found that women presenting with an asthma attack are more likely to be admitted to hospital, have longer hospital visits and receive more medication than men presenting with a similar attack. These findings indicate a pre-existing physician bias, which may reinforce the types of symptoms that men and women associate with a disease diagnosis.<sup>13</sup>

### **American Thoracic Society Epidemiological Questionnaire**

The American Thoracic Society epidemiological questionnaire (ATSQ) is widely used in North America to gather symptom data related to obstructive lung disease (see Appendix B). The ATSQ was adapted from the previously standardized Medical Research Council (MRC) Questionnaire, based on review and consensus from a panel of

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<sup>13</sup> The symptom of chronic cough with phlegm is more often associated with COPD, while wheeze and breathlessness are often thought to represent a more asthmatic type of obstruction, although there is overlap.



experts [7]. Tests of validity were initially conducted by assessing the correlations of symptom reports with FEV<sub>1</sub>% predicted, as well as comparing responses to the MRC questionnaire. A standardized protocol for administration was also developed. Recently, the ATSQ underwent minor revisions based on suggestions from an expert review panel. Respondent interpretation of the ATSQ and the processes that respondents engage in to respond to symptom questions has yet to be explored. Furthermore, the gender sensitivity of the ATSQ has yet to be assessed.

## **V. Summary**

While Kauffman and Becklake [3] make a compelling case for the complex nature of potential sex and gender influences on respiratory symptom perception and reporting, there remains a disconnect between recent advancements in the conceptualization of gender in health research and epidemiological studies revealing differences in men's and women's reports of symptoms in the field of respiratory health. To date, little research has examined the potential influences of gender on cognitive processes involved in responding to survey questions, and no studies have examined potential gender differences in the cognitive processes involved in responding to respiratory health surveys.

Recent revisions to the ATSQ and its release for additional testing makes this an opportune time to examine men's and women's response processes to self-reported respiratory symptom questions. This thesis integrates research on gender, survey methodology and obstructive lung disease in order to illicit men's and women's descriptions of the cognitive and emotive processes that they engaged in when responding to the ATSQ.

### **Chapter Three: Methodology**

This study examined the experiences of men and women when reporting symptoms on the American Thoracic Society Epidemiological Questionnaire (ATSQ) in order to propose a conceptual response framework. The goal of this conceptual framework is to explain the cognitive processes that men and women engage in when formulating responses to respiratory symptom questions and to assess the effects of gender on these processes. This chapter is divided into four sections. The first section provides the rationale for the use of a qualitative approach, including an overview of the grounded theory techniques used in this study. More detailed descriptions of the data collection and analysis methods are provided in Sections Two and Three, including a description of the sampling procedures used. The fourth section includes an overview of the most salient issues pertaining to the assessment of rigor for this study.

#### **I. Qualitative Methodology**

While quantitative studies have noted that men and women provide different patterns of responses to questions regarding respiratory symptoms, limited empirical evidence has been collected to examine the potential influence of psychosocial factors on these differences. Although useful for comparing the prevalence of symptoms across populations, a survey design does not easily expose respondents' perceptions and cognitive processes through which they formulate answers to survey questions about respiratory symptoms. This qualitative study begins to fill a gap in the literature by providing rich descriptions of the cognitive processes that men and women engage in while responding to ATSQ respiratory symptom questions as well as describing the psychosocial factors that affect the response process. The purpose of the study was not to

measure the magnitude of difference, but rather to describe some of the underlying mechanisms that contribute to overall differences in men's and women's responses.

### **Analytic Approach: Drawing on Grounded Theory**

Data collection and analysis takes many forms in qualitative research, but this study was most directly informed by the techniques typically associated with the grounded theory approach<sup>14</sup>. This approach is commonly used to identify and create conceptual representations or models of psycho-social processes (e.g., making decisions about which answer to select on a questionnaire) and is therefore well suited to the goals of this thesis.

The hallmark techniques of grounded theory include: sampling to enhance the theoretical diversity of the sample; concurrent data collection and analysis; multiple step coding process (open, axial, and theoretical coding); the constant comparative method; and integration of the theoretical framework. Memo writing is also an important methodological tool, used to enhance rigor in studies employing a grounded theory approach. Each of these processes will be described in more detail below.

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<sup>14</sup> Grounded theory was first developed by Glaser and Strauss in 1967 [see 94] as an alternative to quantitative research and the lack of theory that accompanied the quantitative approach. They saw the need to get out into the field to see what was really going on from the point of the social actors of the phenomenon of interest to scientists. They used these lay perspectives, along with their own research training and knowledge to develop a method of research that produced theory that was grounded in empirical data, being the experiences and perceptions of participants. Glaser's contribution of a systematic approach to data collection and analysis (based on his positivistic training) and Strauss' contribution of attributing meaning to empirical inquiry through his training in symbolic interactionism, combined to produce a set of "systematic inductive guidelines for collecting and analyzing data to build middle-range theoretical frameworks that explain the collected data" [94, p.509].

## **II. Sampling and Data Collection**

Participants were recruited from the population of study subjects in the Coastal Marine Transportation Workers Study, a longitudinal study which entered its fifth wave in October 2005 [95]. Male (n=20) and female (n=20) employees were recruited to participate in semi-structured interviews regarding their responses to ATSQ respiratory symptom questions. To be eligible, participants had to: (1) be enrolled in the Coastal Marine Transportation Workers Study; (2) have no cognitive impairments; (3) speak fluent English. See Appendix A for characteristics of the sample.

A letter of re-contact was sent to all Coastal Marine Transportation Workers study participants outlining the new option for workers to participate in the semi-structured interview regarding their responses to ATSQ symptom questions. Interviews were scheduled to coincide with data collection dates for the ongoing Coastal Marine Transportation Workers study and were conducted at three locations in Greater Vancouver and 3 locations on Vancouver and SaltSpring Islands. As the study progressed, individual phone calls were made to potential respondents in advance of the interviews in order to ensure that they were aware of the sub-study and of the time commitment required to complete the semi-structured interview, should they choose to participate. The sub-sample of Coastal Marine Transportation Workers study participants who chose to participate in the interviews received an additional consent form for participation in the interview. Respondents did not receive monetary compensation.

The process by which study participants were selected into the sample was purposive and was informed by theoretical sampling principles. Purposive sampling is not based on probability, as would be expected of quantitative studies, but rather is a

deliberate selection of participants based on the experiences and perspectives that they can bring to bear on the question of interest. So, rather than randomly selecting interview participants in order to ensure their “representativeness” of the broader population, I deliberately selected participants who had the capacity to describe a range symptom perception processes. For example, in this study, I hypothesized that knowledge of perceived exposure and the consequences relating to respiratory health of that exposure could influence the ways that men and women interpret and respond to respiratory symptom questions. By selecting participants who had a range of exposure statuses, I purposively attempted to include participants with a range of experiences relating to the processes of symptom perception and reporting. For example, sampling for a range of job titles and smoking status helped me to recruit and select a theoretically rich sample in order to examine the influence of gender at potentially varying levels of exposure (recognizing that job title and smoking are in essence proxies for more precise exposure measures that may be relevant to respiratory health). Purposive sampling also facilitates the selection of a relatively small sample of interview participants (compared to the probability samples required for establishing populations estimates using data gathered through quantitative survey techniques), while still capturing a broad range of experiences and perspectives in order to ensure the development of an encompassing conceptual model.

To understand the influence of gender on self-reports of ATSQ respiratory symptom questions, several factors informed my sampling decisions: exposure history (e.g., smoking, job exposure), knowledge of respiratory disease (e.g., doctor diagnosed asthma), occupational roles (e.g., catering vs. labour), and life stage (i.e., age). Cultural

influences, specifically cultural norms associated with ethnicity, had also been proposed as important potential influences on men's and women's interpretations of and responses to respiratory symptom questions. However, given the lack of ethnic diversity in the Coastal Marine Transportation Workers study population (92% Caucasian [95]), this variable was not feasible to use in the sampling strategy<sup>15</sup>.

With these sampling considerations in mind, I examined the existing Coastal Marine Transportation Workers Study database to determine which participants to invite into my sample. I also sampled employees who had not completed the study in previous years if their answers on the most recent questionnaire led me to believe that they could bring a unique perspective into the sample (e.g., a male who had reported only dyspnea). As my data analysis progressed, I used new data from additional interviews to inform subsequent sampling decisions. For example, after completing the first eight interviews, it became apparent that most the male participants were employed at the shipyard; subsequently, I tailored my recruitment and selection decisions to include males from other job categories (e.g., catering). However, sampling decisions were also constrained by the characteristics of the Coastal Marine Transportation Workers population (e.g., very few men worked in catering). Therefore, my sampling decisions reflected the characteristics of the population (e.g., included more men from labour jobs than from catering jobs).

## **Interviews**

The "Questerviews" technique was used to conduct the interviews.

"Questerviews" is a method whereby a quantitative questionnaire is used to facilitate a

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<sup>15</sup> Furthermore, the influence of ethnicity on gender differences in symptom reporting could itself be a thesis, given the complexity of both of these variables.

qualitative, individual interview about respondents' responses to the quantitative questionnaire. The basic principle of this method is that close-ended questionnaires often have "triggers" that stimulate a respondent to recall, consider, and synthesize experiences related to their health before choosing a response option [96]. "Questerview" techniques exploit respondents' natural tendencies to respond to "triggers" in more detail. The ATSQ was used to facilitate the interviews, along with a semi-structured interview guide that included probes to stimulate respondents to elaborate on their initial answers to the symptom questions. These probes used several techniques to probe cognitive processes: 1) retrospective think-alouds, 2) confidence ratings (where the respondent assesses their confidence in their answers), 3) paraphrasing by the respondent, 4) defining key terms, and 5) probing to reveal response strategies [33]. The interview guide was developed in conjunction with my supervisory committee, and was informed by the existing literature on symptom perception and reporting. The first four interviews that were conducted, acted as a pilot test for the questionnaire. Findings from the pilot test were also used to inform the development of my conceptual model.

The ATSQ<sup>16</sup> was administered by an interviewer for the Coastal Marine Transportation Workers Study as per standardized ATS protocol [7]. Standardized administration protocol calls for the interviewer to ask the respondent each of the ATSQ questions and mark down the response option that the respondent selects. Interviewers are trained not to deviate from the question wording and if the respondent is uncertain of what their response should be, the interviewer is instructed to record a negative

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<sup>16</sup> Respondents were randomly administered either the original (1978) or the revised (2004) version of the ATSQ. My follow-up interviews were probed accordingly. The only significant difference is for the question on wheeze (see footnote 18).

response<sup>17</sup> (i.e., selects the “no” response). Following the completion of main study’s data collection, I interviewed each of the 40 selected participants, inviting them to elaborate on their responses to the symptom portion of the ATSQ. After briefly explaining the purpose and format of the interview, I began by repeating the first, close-ended question in the new ATSQ. I then asked each respondent to explain how s/he interpreted the question, asking each respondent to recall and explain the thoughts and emotions that were experienced as they chose their response option (most response options are yes/no dichotomies). I also asked respondents to draw on their everyday experiences of symptoms in order to provide descriptions of the symptoms on which they were basing their answers to the close-ended questions. Questions were asked to probe the concept of the social acceptability of symptoms and symptom reporting, and to explore a variety of psycho-social factors that might help explain how symptom reporting may differ for men versus women. This process was repeated for each of the five main ATSQ symptom items: cough, phlegm, episodes of cough with phlegm, wheezing, and shortness of breath<sup>18</sup>. Interviews ranged from 5-50 minutes in length and were audiotaped.

After each interview was conducted, I made notes regarding my general impressions of the interview, including participants’ non-verbal reactions to questions, body language used when describing symptoms, and interactions between the participant and myself as the interviewer. As the interviews progressed, I was able to assess areas

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<sup>17</sup> See Appendix B for full ATSQ and interviewer instructions.

<sup>18</sup> Note that due to time constraints, often only the initial question for each item was probed. Questions included: (1) Do you usually have a cough?; (2) Do you usually bring up phlegm from your chest?; (3) In the past 12 months, have you had periods or episodes of cough with phlegm that lasted 1 week or more?; (4) Does your chest ever sound wheezy or whistling? (original) or Have you ever had wheezing or whistling in your chest? (revised); (5) Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill? Follow-up questions were only discussed if they were mentioned by the respondent.



where the interview guide required revision. For example, it became apparent that being diagnosed by a doctor as having a respiratory disease could influence how men and women experienced and made note of symptoms. Therefore, new probes focusing on doctor diagnoses were added to attempt to tap into this potential influence on symptom reporting. As well, some respondents found the interview guide to be repetitive, as probes were similar for each of the five symptoms. Therefore, in later interviews, I deleted probes that were found to be repetitive and were not garnering new dialogue from respondents. The interview questions served as a “guide” and interviews sometimes took on a life of their own, depending on the experiences of the respondent and interactions between the participant and myself.

Audiotapes of the interviews were transcribed in order to accurately capture the descriptions provided by respondents (transcripts were also checked against the tapes to ensure their accuracy). To ensure confidentiality, individual identifiers were removed from transcripts and participants were assigned an alias. Informed consent forms and audiotapes were stored in a locked file cabinet for the duration of the study. They will be stored securely for five years after the completion of the study at which point consent forms will be shredded and audio-tapes will be erased.

### **III. Data Analysis**

Qualitative data collection and analysis is an iterative process, with coding informing decisions about subsequent sampling and interview questions and vice versa. Therefore, analysis of the interview data started after four interviews were conducted and continued throughout the data collection process. This early analysis also informed revision decisions to the interview guide (as described above). Coding and writing about

the findings also occur in tandem – writing about the meaning of each code as it is assigned and writing about the emerging hypotheses of how the various codes fit together happened concurrently.

### **Coding**

The general aim of the analysis is to compare and contrast the ways in which men and women interpret/define symptom questions, describe the cognitive processes that they engage in while selecting response options, and identify how gender affects these processes. Coding is the process of developing conceptual labels that characterize descriptions in the data. Three levels of coding were used during the analysis process of this study: open, axial, and theoretical-style coding. These coding processes will be described in more detail below.

In order to familiarize myself with incoming data, I completed a rough transcription of each of the eight initial interviews (i.e., not verbatim). This familiarization with the data helped to inform revision decisions to the interview guide, allowed me to refine my interviewing style, and acted as a starting off point for the coding process. It also made it possible to begin preliminary analysis in advance of receiving the finalized transcripts, which are time consuming to prepare. Rough transcripts and interview tapes were then given to a transcriptionist and were transcribed verbatim so as to capture intonations of voice, pauses and hesitations, slang language, imitations of symptoms used by respondents, and accurate interactions between the interviewer and the participant (e.g., affirmation from interviewer). As well, the transcriptionist removed all unique identifiers that emerged during the interviews (e.g., names). I then reviewed each tape and transcript to check for accuracy and the complete

removal of all potential individual identifiers. The process of accuracy checking also assisted me in re-familiarizing myself with initial data and the emergent concepts in the data, informing testing and/or re-affirming coding decisions. Reviewed transcripts were then uploaded using NVIVO software to assist with data management during the more advanced stages of coding.

### *Open Coding*

In the open coding stage of data analysis, I developed an initial set of codes (i.e., abstract, conceptual labels) that represented the key processes described by men and women. This was achieved by completing line-by-line analysis of the raw data. At this initial stage, many of my codes included the words of participants (e.g., the descriptive terms they used, the metaphors they employed). The aim of the open, line-by-line coding process (i.e., attention to specific words used and meanings of sentences) is to break down the data into discrete parts to look for all possible emerging categories. Open coding is used to sensitize the researcher to possible themes in the data that may otherwise be overlooked.

The open coding process began after the initial week of data collection where eight interviews were conducted. Rough transcripts were printed out and emerging concepts were highlighted. As well, I made notes in the margins about why I thought specific concepts were important to the analysis and identified “gem” quotes that contained what I considered at that point in the analysis, to be the richest descriptions of important concepts. During open coding, I attempted to identify each new idea that emerged from respondents’ dialogue.

### **Figure 3.1: Example of Open Coding Process**

*Interviewer: And um what do you think it would take for a person to answer, "Yes" to this question?*

*Interviewee: If they had asthma [labelling] or under frequent- under a doctor's care [Dr. diagnosis] because with a lot of chronic health problems, because they come on slowly [comes on slowly], people don't see the wheezing or say [sic] the wheezing as the problem [not a problem] until someone says to them, "Gee you should see a doctor. You don't sound too good" [other's noticing]. But they think because it's- comes on gradually [comes on slowly], you believe it's a norm [it's normal] you know, you don't pick up on it- this being a problem [not a problem].*

#### *Axial Coding*

As the analysis progressed and additional interviews were conducted, I began to group the initial codes into more abstract conceptual categories through the process of axial coding—defined by Corbin and Strauss [97] as coding “around the axis of a category, linking categories at the level of properties and dimensions.” During this axial coding process, initial descriptive codes or categories were grouped into more abstract conceptual categories, helping to move the analysis beyond simple description. At this point, I began to look for relationships between sets of codes in order to begin to build a nascent conceptual model of the processes that respondents engage in when selecting responses on the ATSQ. For example, codes such as ‘induced by exercise,’ ‘induced by smoking,’ ‘induced by sick environment,’ and ‘resulting from stress’ were combined to form the code “situating.” Each of the initial open codes became components of the overarching process of “situating” a symptom in the context within which it occurs. This re-merging of data (i.e., open codes to axial codes) organizes concepts according to theoretical links between the open codes, based on similarities and differences of

dimensions or properties of the open codes and is assisted by knowledge from the existing literature and personal experience.

Even in this more advanced stage of the data analysis, I continued to use my interview data to inform decisions about what kinds of data to attempt to collect next (e.g., add new questions to interview guide to more deeply explore an emerging concept, including new concepts on which to sample). I continued to check axial codes against the incoming data to ensure “fit” of new dialogues to existing conceptualizations. Gaps were identified and axial codes were enhanced to account for new perspectives and experiences. Data that did not “fit” with existing conceptual categories were not ignored. Rather, these perspectives were taken into consideration in order to improve the fit and scope of the emerging theory.

The axial coding stage yielded the development of my initial symptom perception and reporting model. Although this model was subsequently refined, the basis for the model was developed through axial coding. During axial coding, I began to think about differences in the ways in which men’s and women’s descriptions of the processes that they engaged in and factors that they drew upon to choose responses.

#### *Theoretical-Style Coding*

In the theoretical-style coding phase, the emerging conceptual model was refined and solidified. Analytical questions were asked of the data; potential links between conceptual categories (i.e., axial codes) were further examined to solidify or modify the proposed relationships amongst concepts that were included in the emerging model. At this point, I challenged myself to see alternative explanations and perspectives that had not been adequately accounted for in the initial coding and model development. In this

final stage, I moved back and forth between the empirical data, the literature, and my most abstract conceptualizations of the emergent model, tying the data together, in order to test and re-test my hypotheses about the fit between my raw data and the conceptual representation that was emerging.

I used diagrams to illustrate and “pin down” potential hypotheses about relationships and patterns in the data. Initially, these diagrams were formulated to represent general processes of symptom perception and reporting that both men and women seemed to engage in. As the analysis progressed, I used diagrams to compare and contrast men’s and women’s narratives in order to ascertain potential differences in the fit of the model for men as compared to women. I also used the diagrams to examine other psycho-social factors (e.g., occupational influences, differences in health seeking behaviour) that could lead to differential (and similar) experiences of symptoms. The results of this study are summarized in a conceptual model (i.e., a final diagram). The model is accompanied by a more detailed explanation (i.e., an emergent theory) of the processes that both men and women engage in when reporting respiratory symptoms and the ways in which external gender-related, psychosocial factors affect these processes.

#### **IV. Issues of Rigor**

While findings from this study are not intended to be generalizable, it is important to recognize the unique characteristics of this relatively healthy, mostly working population. Although some men and women within the Coastal Marine Transportation Workers sample are employed in “non-traditional” job categories (e.g., men in catering, women shipyard employees), there remains a gendered segregation of labour, where many of the women are employed in traditionally feminine job areas such as catering and

cleaning, while most male employees maintain more traditionally masculine jobs such as ship engineers and tradesmen (i.e., shipyard employees). Therefore, this sample provides a unique opportunity to examine both men and women in traditional and non-traditional occupational roles.

Conducting data collection in conjunction with the Coastal Marine Transportation Workers Study offered both benefits and limitations. I was able to use data from the previous waves of the study to purposively sample study participants (which also facilitated contacting respondents and scheduling of interviews). The inclusion of the ATSQ in the Coastal Marine Transportation Workers Study also made it possible for me to employ the “questerviews” technique, something that has not yet been documented in respiratory research or in occupation health studies. However, because my data collection was tied to the Coastal Marine Transportation Workers Study period, my data collection period was fairly condensed for a qualitative project. Given that I was drawing on the principles of grounded theory for my analytical approach, it was a challenge to keep on top of the incoming data, in order to make decisions about what kinds of data to collect next. However, I did meet with my committee after each week of data collection to gather their feedback. Dr. Shoveller also conducted one of the interviews at the mid-way point of data collection in order to provide an additional perspective on the development of new probes and illustrate various techniques used to elicit detailed responses from respondents. I also was able to select interview sites to maximize the amount of time between interviews in order to concurrently analyze data.

### **Use of Semi-Structured Interview Guide and Questerviews Technique**

The cognitive and affective processes involved in symptom reporting exist as somewhat innate behaviour for most people. For this reason, the interviews were constructed in such a manner as to help participants reflect on and describe their perceptions and experiences (i.e., to help people to describe the somewhat abstract concept of reporting a symptom). For example, it was often challenging for respondents to state how they would define the symptom of cough. Therefore, I would provide them with example definitions, such as “a clearing of the throat,” or, “a deep, hacking cough,” and ask them to review which type of cough they considered when they responded to the question, “Do you usually have a cough?”

Probing questions were used to stimulate respondents to consider specific factors that may have “run through their mind” when deciding if they experienced a symptom. For example, the term “usually” (which appears in two of the ATSQ items I examined) was probed in order to encourage respondents to elaborate on how they interpreted the question, “Do you usually have a cough?”

### **Member Checking**

As interviews progressed, I began to share concepts that had emerged from previous interviews with new respondents as part of the interview guide. This form of member checking helped to stimulate respondents to critique or add to the experiences and perceptions of other respondents. This process helped me to ensure that varied aspects of a phenomenon were captured during my interviews and to ensure that dissenting perspectives that did not conform to the status quo were captured. For example, many respondents provided lay theories regarding reasons for differences in



men's and women's symptom experiences. By summarizing these lay theories to respondents in subsequent interviews, I was able to capture both agreements and disagreements to previously reported lay theories.

### **Interview Notes, Self-Reflexivity, and Relationality**

Making notes on the interview *process* (in addition to *content*) not only enhanced data collection by highlighting potential changes to the interview guide or areas that needed to be probed, it also provided an opportunity to engage in reflexivity and relationality. Reflexivity refers to the process of addressing the influence of interactions between the interviewer and the respondent during the interview process. Relationality refers to the process of addressing issues of power and trust in the relationship between the interviewer and the respondent [98].

Because the current study focuses on the effects of gender on symptom reporting behaviour, it was important for me to be aware of potential gendered interactions between myself and the respondents. Therefore, after each interview, I made notes about our interactions, with attention to the potential influence of gender on these interactions (e.g., jokes made by respondents (especially male respondents), and my responses to their statements). These notes also included descriptions of the participants' (and my own) dress and body language. I also described interruptions to the interview (e.g., a fire alarm), the quality of the interactions between the respondent and myself (e.g., tensions, my thoughts on how they perceived me and how this may have influenced my/their comfort during the interview) and my immediate thoughts on how to improve the next interview. These notes were useful as I reflected on my reactions to respondents (e.g., whether or not I viewed the respondent as being stereotypically feminine or masculine)

and how these reactions may have influenced the interview process (e.g., the flow of the interview), the way I asked questions (e.g., the wording of my probes) and my analysis (e.g., how the influence of gender on symptom reporting was maintained during my interviews). I also attempted to make notes of how the respondent appeared to react to my self-presentation during the interview and to reflect on the ways those reactions may have affected the flow of the interview.

As I analyzed the data, I tried to remain cognizant of the many ways in which our interactions during the interviews may have influenced respondents' presentations of their gendered-selves (e.g., male respondents may have felt the need to maintain "a masculine" self-identity in front of myself, as a female interviewer). I also attended to inconsistencies in the narratives told, pauses and hesitations, and tone of voice, to enhance my understanding of how interviewer-respondent interactions may have influenced the responses formulated by respondents<sup>19</sup>. For example, I noted during one interview with a female respondent, that when asked about potential gender differences, her tone of voice became terse and her dialogue was very assertive about the fact that she would cough and spit if she needed to, with no apologies. I was conscience of the fact that her response may have, in part, been a reaction to her feeling of being judged by my interpretation of her gender identity during the interview<sup>20</sup>. In addition, throughout the course of the thesis, I kept detailed notes regarding my analytic decisions. Together, these notes, with the notes I have made on reflexivity and relationality, constitute what is sometimes referred to as an "audit trail," which I hope lends credibility to the findings.

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<sup>19</sup> This process is referred to by Poirier and Aryse [99] as "overreading."

<sup>20</sup> She had previously worked as a shore-worker, a traditionally masculine job occupation and I perceived her as identifying with more masculine characteristics.

## **V. Ethical Considerations**

Ethical approval to conduct the interviews for this thesis was granted by the University of British Columbia Clinical Research Committee (Certificate of Approval number C05-0398). A copy of the ethics application is included in Appendix E. As this study was one component of an extensive study on the respiratory morbidity of coastal marine employees and retirees, my major ethical concern pertained to participant burden. In response, I kept my interviews as brief as possible so that respondents were not overburdened by the length of the overall study process.

## **CHAPTER FOUR: FINDINGS**

While models of symptom reporting have been developed in other fields of health research (e.g., cognitive aspects of self-reported health), no research has examined the cognitive processes that individuals engage in when responding to respiratory symptom questionnaires, and specifically to the American Thoracic Society Questionnaire (ATSQ). Additionally, little research has been conducted on possible gender differences in cognitive processes of responding to health questionnaires. While there is evidence of gender differences in the reporting of respiratory symptoms, little is known about the reasons for these observed differences.

Through the use of grounded theory methods, a theoretical framework emerged for beginning to understand the cognitive processes that men and women engaged in when responding to the ATSQ. This chapter introduces the findings and describes each component of the framework, which culminates in the process of *integrating to normalize or de-normalize symptoms*. While the emergent model was found to be similar for men and women, the chapter concludes with an analysis of gender influences on the cognitive processes involved in responding to the ATSQ.

### **I. Characteristics of the Sample**

The sample consisted of 20 men and 20 women, with an average age of 57 and 58 respectively (see Appendix A for a detailed description of the characteristics of the sample). More women in this sample worked in catering and office/administration positions, while more men worked in the shipyard and engineering positions. Eight women and five men reported no symptoms, while the remainder reported one or more symptoms. Four women were current smokers; ten were ex-smokers, and six had never

smoked. Two men were current smokers, six were ex-smokers, and twelve were never smokers.

## II. Overview of the Emergent Conceptual Model

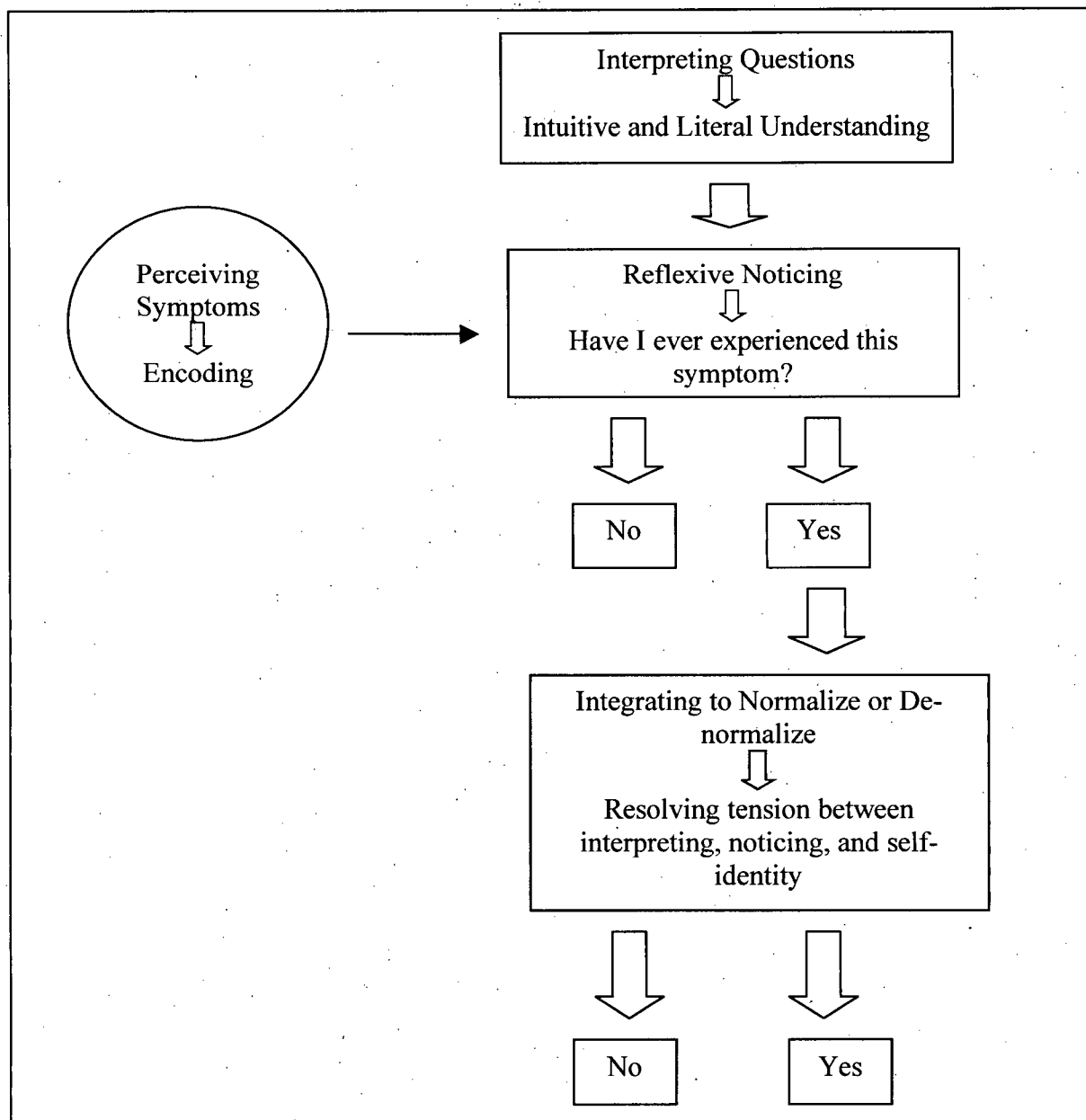
The emergent conceptual model was developed based on respondents' thoughts and discussions of their experiences answering the ATSQ during the 2005 wave of the Coastal Marine Transportation Workers study. I begin by outlining a general framework that summarizes the processes that both men and women engaged in. I then draw comparisons between men and women regarding the factors that contributed to decision making at each stage of the model (e.g., the influence of masculinities and femininities, structural influences of gender, and respondents' lay theories of gender).

The conceptual model outlined below (Figure 4.1) delineates the cognitive processes that individuals engaged in to understand, interpret, and respond to the ATSQ questions that were posed by the interviewer. The framework consists of three levels of cognitive processes. The first process, called *interpreting*, describes how respondents came to formulate an understanding of the research questions (literal interpretation) and the overall goal of the research process (intuitive interpretation). During the second process of *reflexive noticing*, respondents engaged in recall to determine if they had experienced the symptom in question. During *integrating to normalize or de-normalize*, the third process, respondents came to determine the significance of the symptom that they recalled having experienced during the *reflexive noticing* process (e.g., is this symptom significant enough to report on the ATSQ?). In this final process, the stages of *interpreting* and *reflexive noticing* were *integrated* to form a final reporting decision (i.e., yes or no).

The cognitive response processes outlined above were found to be influenced by respondents' prior *perceptions of symptoms*. The degree to which a respondent had perceived symptoms and encoded their symptom experiences prior to entering the research setting influenced the ease with which they engaged in reporting processes and formed reporting decisions during the research interview. Many respondents had formed assessments of their respiratory symptoms and health prior to entering the research setting and easily integrated their interpretations of the questions with their reflexive noticing of symptoms, regardless of whether they had formed more literal or intuitively-based interpretations of the questions. The same straightforward response process was true for respondents who, although they may not have previously given much thought to their respiratory symptoms or health, did not recall experiences with the symptom in question that matched either their literal or intuitive interpretations of questions. For both of these respondents, self-definition of their health status aligned with their recall of symptom experiences during the *reflexive noticing* process.

However, a subset of respondents struggled to *integrate* their literal and intuitive interpretations of the questions and their *reflexive noticing* given their self-identity as being a person who is "free from lung disease." In other words, while some respondents intrinsically viewed themselves as very healthy, they recalled experiencing ATSQ symptoms during their reflexive noticing process. In this case, the process of *integrating to normalize* or *de-normalize* was the product of emotive tensions experienced by respondents' attempts to reconcile their *interpretations* of ATSQ questions (literal and intuitive), *reflexive noticing* of symptoms, and self-identity.

**Figure 4.1: Emergent Conceptual Model**



### III. Perceiving Symptoms

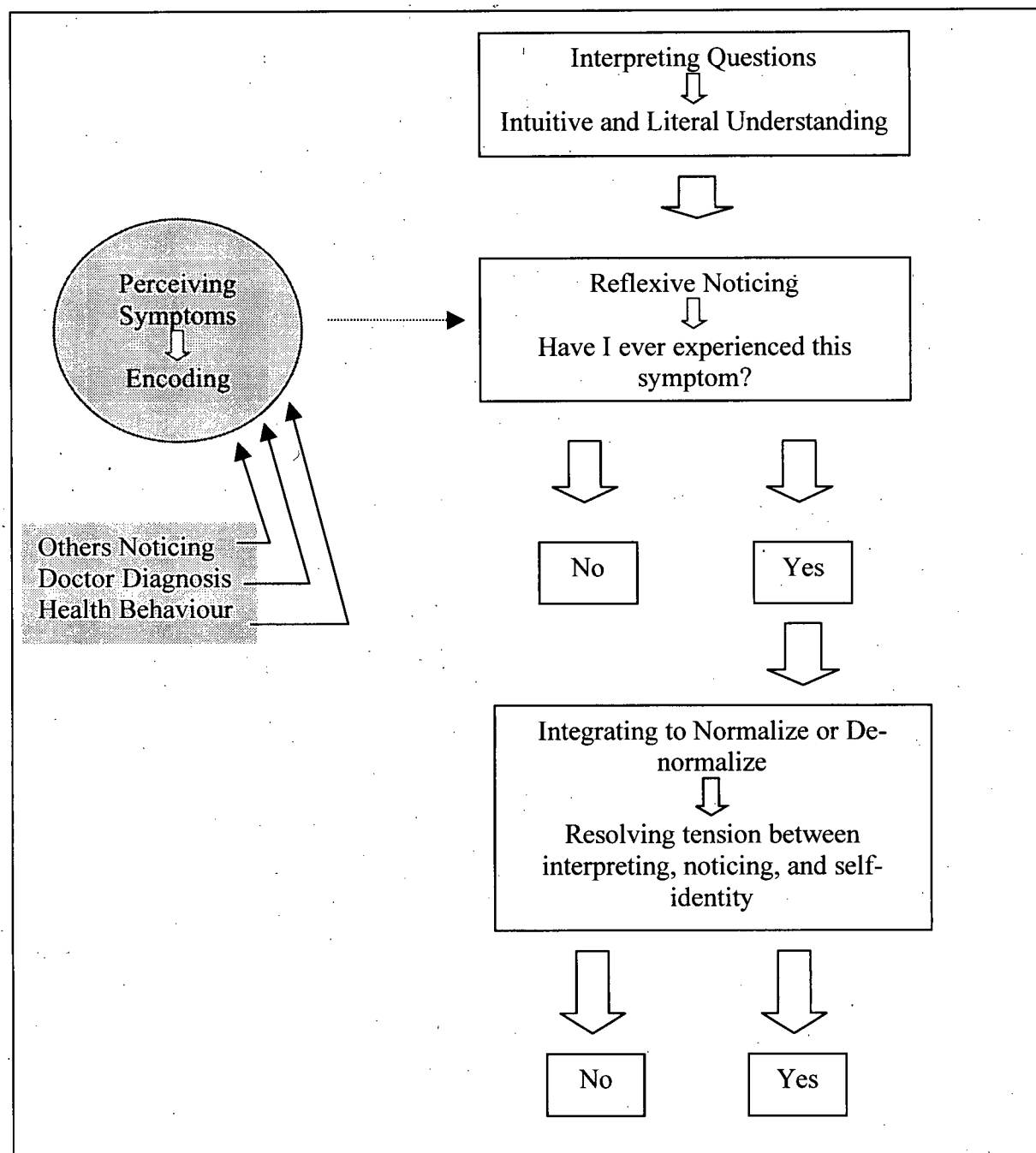
The process of *perceiving symptoms* refers to respondents' discussions of how they had initially come to perceive an ATSQ symptom in their day-to-day life. In this context, *perceiving symptoms* happened prior to entering the research interview and influenced the reporting processes engaged in by respondents. The process of *perceiving*

*symptoms* not only influenced whether a respondent remembered noticing an ATSQ symptom (i.e., *reflexive noticing*), but perceiving symptoms also influenced the degree to which respondents believed that a symptom was important to report (i.e., *integrating to normalize or de-normalize*); this type of process is referred to in the literature on cognitive aspects of survey methodology as prior *encoding* of relevant information [33].

Prior perception of symptoms (or the absence of symptoms), led many respondents to form a self-identity as healthy (or un-healthy) and, in relation to the ATSQ, their respiratory health status (i.e., encoding). Furthermore, prior encoding processes also led some respondents to normalize symptoms that they had perceived prior to entering the research setting. In other words, even if a respondent had perceived symptoms, this did not imply that they had encoded their symptoms as problematic. Other respondents discussed not having thought about whether they had noticed a symptom prior to being administered the ATSQ and had not formed an identity of their health in relation to the symptom in question or because they had not given their symptoms much thought, intuitively defined themselves as healthy. It was these respondents, in particular, whose discussions illustrated an emotive tension during the *integrating to normalize or de-normalize* phase. Respondents' prior symptom perception was influenced by others noticing, having received a previous diagnosis, and health behaviour (see Figure 4.2 below).



**Figure 4.2: Perceiving Symptom Stage of the Emergent Conceptual Model**



### **Others Noticing**

Many of the respondents described how other people noticing or mentioning their symptoms affected their own perceptions about symptoms and ultimately their responses

to the ATSQ. Men talked more often about their partners noticing their symptoms before they did. For example, Frank stated that: "... I forget about it and I get reminded by my wife that I'm breathing heavy, or that I seem to be laboured breathing and I don't notice it." The women also talked about noticing and commenting on their male partners' symptoms as illustrated by the following quote from Heather, "my boyfriend is having this cough and I keep saying, "You better go get that checked out." Two women described how their family had noticed their health, one in terms of her children being concerned about her "coughing fits" (she has asthma) and the other in terms of her husband and her kids "nagging" her to quit smoking. These examples illustrate how other people commenting on a respondent's symptoms could lead them to initially be more aware of their symptoms and hence more likely to remember them when asked to recall an ATSQ symptom. Heather summarized this process:

"... if they have it all the time I think they don't notice it, just accept it and carry on. It might take somebody else to notice it and say "I think you better go get that checked out." Everybody's busy in their life, carry on."

While others' noticing and commenting on respondents' symptoms led many of them to encode their experience and to form a self-identity as someone who undeniably experiences ATSQ symptom(s), some respondents discussed how others' noticing their symptoms actually led to feelings of guilt and hence further denial of their symptoms or their respiratory health status. For example, Carol, a 46 year old smoker, talked about how her children and husband used to "nag" her about how much she smoked. However, she could not give up smoking and therefore attempted to hide her smoking behaviour from her family. She suggested that her guilt about her smoking had also led her to deny having experienced ATSQ symptoms on earlier waves of the Coastal Marine Transportation Workers Study (she currently reported all

symptoms except episodes of cough with phlegm). Therefore, it seems that others' noticing may not only lead to increased awareness and encoding of ATSQ symptoms, but it might also enhance feelings of guilt and responsibility regarding poor lung health. This concept is discussed in more detail in the section on health behaviour.

### **Having a Medical Diagnosis**

Having had a doctor or health practitioner diagnose a symptom (e.g., wheeze) or a disease related to a symptom (e.g., asthma) increased the likelihood that respondents had initially noticed symptoms. For example, Patty said it was easy for her to answer the question about wheeze as illustrated in the following quote:

"Well, the doctor said there's a small wheeze in the very bottom. So that's why I said "yes" because the doctor told me." (Patty).

She also indicated that if the doctor had not told her that he could hear a wheeze (with his stethoscope), she would not have noticed it herself. Noah also described how his prior experience with a diagnosed disease influenced the degree to which he perceived the symptom of shortness of breath:

"Well, I know when I do that, I watch that all the time, because I have had congested heart failure, as well, and I know what's [sic] that like. So I'm aware of my breathing and my walking, all the time." (Noah).

While having received a medical diagnosis was discussed as being a significant factor affecting whether a respondent noticed a symptom, receiving a diagnosis also affected the degree to which respondents became concerned about the symptom(s) in terms of their health<sup>21</sup>. An excerpt from Bertha's interview illustrates how some

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<sup>21</sup> One respondent also discussed how not receiving a doctor's diagnosis influenced her encoding of a symptom as normal: "So I have to live with it and I don't worry about it because I have my doctor examination and he would tell me if it's something wrong" (Beth).

respondents may become accustomed to symptoms (or deny symptoms) until a medical diagnosis leads them to define the symptoms as problematic:

“[Interviewer: ... the doctor [sic] diagnosis maybe made you more aware of your symptoms?] Bertha: Yes. Yeah. Or that it was actually a problem [laughs]. I guess I like to live in a, in denial. I just don't want to deal with it; so, I'm fine.”

This process of determining the significance of a symptom occurred prior to Bertha entering the research setting and therefore not only influenced the degree to which she recalled noticing her symptom, but also how easily she was able to define the symptom as *de-normalized* given that she now identified as a person with asthma (as a long-term smoker, Bertha's example will be further discussed below in relation to how her smoking affected her prior encoding of symptoms as normalized).

### **Health Behaviour**

Many respondents discussed their health behaviour as having influenced the degree to which they would initially perceive a symptom in their day-to-day lives. For example, the following excerpt from an interview with Doris illustrated how the level of physical activity that an individual engaged in, influenced how likely they were to initially perceive shortness of breath:

“[Interviewer: How long of a distance do you think- just walking at a normal pace- would it take before you would start to experience any sort of feelings of shortness of breath?] Doris: Um, well it's hard to say because I don't, I don't walk more than three blocks.”

Many respondents also discussed how an increase in physical activity could trigger their taking notice of shortness of breath almost immediately, since it interfered with their activities (especially if they considered themselves to be highly physically active):

“... it's really weird cause I play volleyball all the time and I'm very active and I go up a couple stairs and I'm tight and short of breath and I'm going “What's this all about?” So, I thought something's not right here” (Heather).

However, respondents also reported having decreased their physical activity as a method of preventing the symptom that they experienced. In this adaptive mode, after decreasing their level of activity, they would no longer notice experiencing the symptom. For example, Frank discussed why he had previously reported shortness of breath in an earlier wave of the Coastal Marine Transportation Workers Study, but did not report shortness of breath during this most recent wave of the Coastal Marine Transportation Workers study:

“... I don’t do that sort of thing that much or anything too strenuous. So maybe I don’t put the demands on my breathing as I used to.” (Frank).

When I asked for more detail, Frank explained that he did not feel that his health had physically improved; however, he had simply modified his level of activity so that he no longer experienced shortness of breath and therefore no longer thought it was appropriate to report shortness of breath in response to the ATSQ.

Smoking behaviour was also a significant factor in respondents’ discussions of perceiving symptoms, both for smokers and non-smokers. Many of the respondents who were not smokers described smoking as the major cause of respiratory disease. They also viewed smoking as an individual choice and, therefore, they also portrayed the experience of having symptoms associated with poor respiratory health in individual terms. This was well illustrated by Wendy who said:

“I...know of the type of people who do, which I immediately think smokers... I worked as a retail cashier in drug-stores selling cigarettes to people [raises her voice in irony] which wasn’t a very nice thing to do and I would hear them coughing as they bought their cigarettes, as they walked out the door, lighted their cigarettes and coughed some more. [...] You want to shake them, “Don’t do that to yourself.””

Furthermore, since there is a much publicized association between smoking and lung disease (e.g., warning labels on cigarette packages themselves), many respondents who

were not smokers implied that they did not need to be concerned about their respiratory health (e.g., defined ATSQ symptoms as smokers' symptoms).

Respondents who defined themselves as smokers also struggled with the knowledge that smoking is a known cause of respiratory disease. To this effect, they saw themselves as causing their negative lung health symptoms, which at times led them to deny their symptoms. For example, Carol discussed how she would not have chosen to participate in the study if she had *not* been a smoker. Her smoking enhanced her level of awareness about her symptoms; it also heightened her concern about the reason she might be experiencing symptoms:

"It only concerns me because I'm a smoker. So, when I have that [a cough] I think, "Is this because of the smoking?" And I feel guilty because you're smoking and you know." (Carol).

While Carol reported the symptoms of cough and breathlessness on the most recent wave of the Coastal Marine Transportation Workers study because of her smoking, she discussed how on prior waves her guilt regarding her continued smoking had led her to deny the symptoms she experienced. Bertha also discussed how her self-identity as a smoker had previously led her to normalize her symptom of cough. In the following quote she described why she had not reported her symptom of cough on previous waves of the Coastal Marine Transportation Workers study:

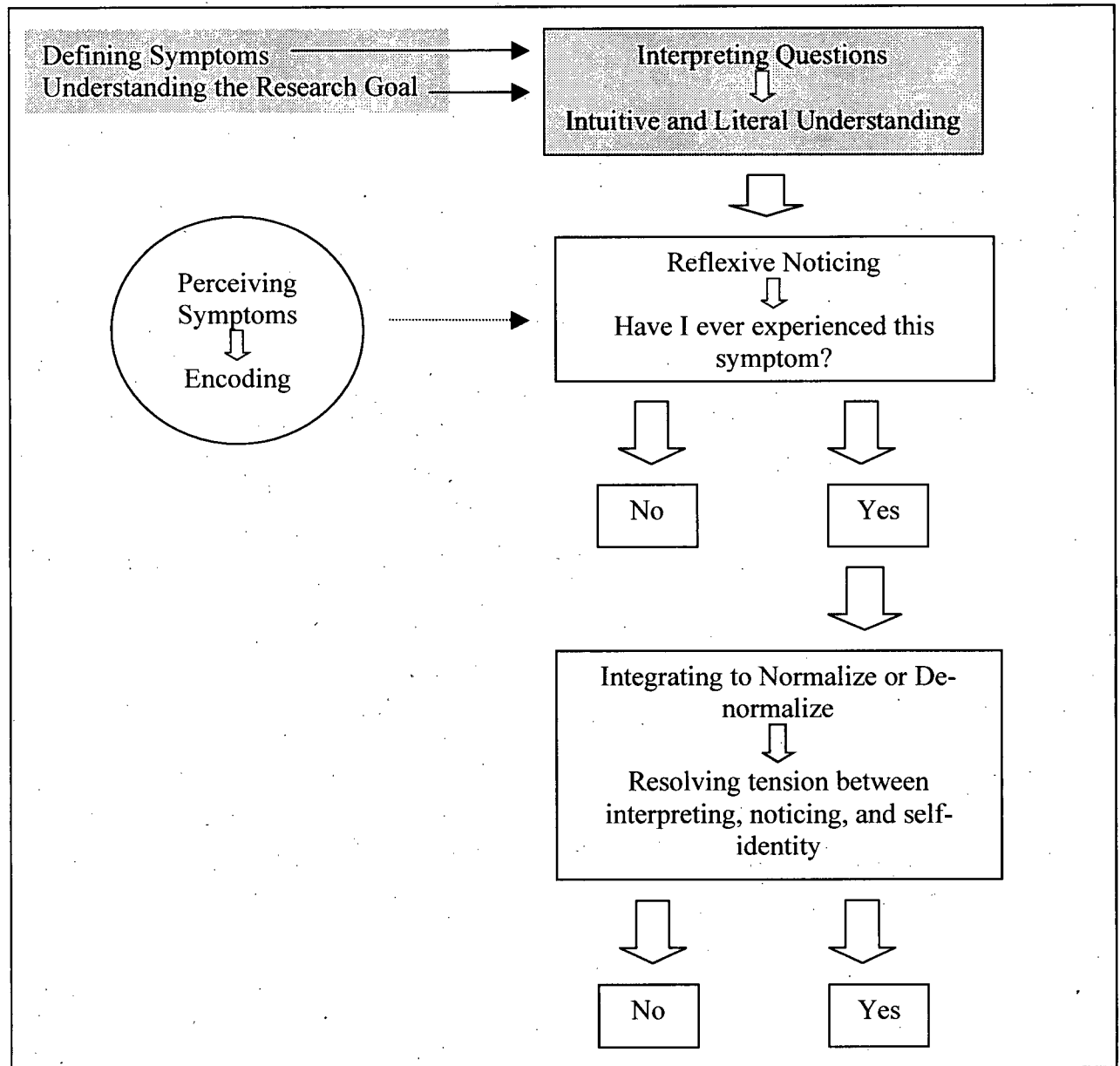
"Well, I don't ever remember not having a cough 'cause both my parents smoked and I smoked [clears throat]. I just didn't think anything of it. I just thought that was normal." (Bertha).

Bertha's quote illustrates how a person's self-identity as a smoker may be intricately tied with the development of lung disease, to the point where symptoms become a normal part of a smoker's self-identity.

#### **IV. Interpreting Questions: Defining Symptoms and Understanding the Research Goal**

Respondents discussed forming both literal and intuitive interpretations of the ATSQ questions that had been asked of them during the Coastal Marine Transportation Workers study protocol. For example, respondents discussed their literal interpretations of ATSQ questions regarding what a cough would look or sound like, what it meant to be troubled by shortness of breath, or how often “usually” would be. In addition, respondents discussed the intuitive interpretations they had formed of ATSQ questions (e.g., the types of people they defined as “usual coughers” and the types of people the research project was attempting to identify through the ATSQ questions). *Defining symptoms* and *understanding the research objective* are two concepts that influence the process of *interpreting questions* (see Figure 4.3 below).

**Figure 4.3: Interpreting Stage of Emergent Conceptual Model**



### Defining Symptoms

When respondents reflected on the questions that they had been asked during the Coastal Marine Transportation Workers Study, they frequently discussed the definitions they had formulated of the ATSQ symptoms (i.e., the process of *defining symptoms*). For



items that addressed common symptoms (e.g., cough), many respondents simply stated that a cough was a cough and they did not appear to have any problem defining the symptom. This was especially pertinent for people who were certain that they had “never” experienced a usual cough before or, conversely, those who easily defined themselves as a “usual cougher” (this connection with *reflexive noticing* will be discussed in the upcoming section). This uncomplicated *defining of symptoms* was influenced by prior encoding of self as healthy or unhealthy (as discussed in the section on *perceiving symptoms*).

Other respondents thought more carefully and provided more detailed descriptions of how they would define specific symptoms. For example, Isabelle defined “cough” in the following way: “Uh when I think of a cough, I’m thinking of something that’s more of a cold-style cough rather than a...rasping- fighting for breath kind of cough.” Some respondents found the process of defining symptoms challenging as they were uncertain about the type of symptom that the ATSQ was requesting. James’ definition of phlegm provides a good example of the more in-depth symptom definition processes that many participants engaged in:

“...cause it says *usually*, well I mean, when you clear your throat there is always something, whether or not it’s phlegm, it’s actually I don’t know. I mean phlegm to me, it’s kinda, you know, a little more solid type rather than a you know, just general spit.” (James).

The symptom of wheeze was not easily defined by many respondents. For example, Nancy paused and reflected aloud at one point during our interview and said, “You know I really don’t know what wheezing is really”, while Gary described his wheeze as follows:

“... if I’m watching TV and it bores you, my head falls back and I [zzzzz – he imitated his snoring] you know. I wake myself up when I snore or something like that.”

Many respondents were uncertain of the difference between shortness of breath and wheeze. Several respondents suggested that wheeze was a symptom that was “just there” and did not subside after ceasing physical exertion, whereas shortness of breath was perceived to dissipate once they stopped engaging in the strenuous activity.

Respondents described how certain words in the questions had triggered them to define the ATSQ symptoms. The trigger word, “usually,” found in the questions, “Do you usually have a cough?” and “Do you usually bring up phlegm from your chest?”, captured the attention of many respondents, as illustrated by Victoria:

“Well it’s because I do have a cough. Like right now, I’ve got a bit of a tickle in my throat, I got a cough but it’s not *usually*. So I had to think, well how often would “usually” be? So I went with the word “usually” and what I wrote is “no.”

By paying attention to the trigger word “usually,” Victoria and other respondents interpreted the question to refer to a symptom that is an ongoing concern, rather than something that has happened occasionally in the past.

Many respondents described being uncertain about how the question, “In the last 12 months, have you experienced periods or episodes of cough with phlegm, lasting one week or longer?” differed from the questions, “Do you usually have a cough?” and “Do you usually bring up phlegm from your chest?” They perceived that both referred to chronic conditions, although respondents who interpreted the question as referring to a flu or chest cold type symptom discussed having paid attention to the phrases “In the last 12 months,” and “one week or longer.”

When describing their interpretations of the question, “Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill?”

respondents most frequently attended to the qualifier "slight hill" which triggered them to recall situations where they had experienced shortness of breath (*reflexive noticing*). This led them to think about climbing stairs or walking up hills. As Scott said:

"I get shortness of breath when I walk up hills, because we are just not used to it, we are always walking in the flat lands of Delta [laughing]. So, you start walking up a hill and you know, you start sucking wind."

Others, however, discussed struggling to formulate an understanding of the ATSQ shortness of breath question and when probed about potential "trigger words," realised that they had missed key question components that would have helped them to define the ATSQ symptom, as illustrated by Sylvia's response:

*Sylvia:* And I had to think about that one because that's like on flat ground, no but you know, if I'm a couple of steps, just depends on how fast I'm walking or if I'm- yeah I mean I sort of thought about it a second like, "Do you walk like that all the time?" Or how often you are affected by. And how much is winded, I mean, the degree- [*Interviewer:* So what it means by "troubled by"?] *Sylvia:* I would say "troubled." I guess you really need to listen to the question.

While the process of defining symptoms according to question triggers is based on literal interpretations of the ATSQ questions, some question triggers, such as the word *usually*, also led respondents to form more intuitive definitions of the ATSQ symptoms. One process that respondents engaged in which led to more intuitive definitions of the ATSQ questions was *comparing to others*.

#### *Comparing oneself to others*

By *comparing themselves to others*, respondents formed a mental representation of the symptom they were being asked about (e.g., how would a person who is suffering from shortness of breath appear?). Many of the respondents discussed noticing other people who had experienced the symptom, and, therefore, had come to define the ATSQ symptom according to what they had noticed in other people. For example, when Adam

discussed how he would describe the symptom of wheeze he stated that his reasoning was based on information that he had gathered based on observing other people experience this symptom: "So that's why- how I went by the question, from what I've heard in others." This process led to both literal definitions of symptoms (i.e., what the symptoms looked or sounded like) and formed the basis for subsequent intuitive interpretations of symptom questions by establishing the "types" of people who would experience the ATSQ symptoms.

Respondents often asserted that particular types of people (especially smokers) were associated with specific symptoms (especially cough) and they used those associations to define their interpretation of an ATSQ symptom. For example, Beth defined the symptom of cough as follows: "You know I'm thinking of people I know who've smoked all their lives and coughed constantly, so that's the way I'm looking at it too." Frank extends this association to discuss what his definition of a smoker's cough sounds like:

"Usually, well I usually think of smokers, because of that, because I have lived with smokers. Usually it's a dry cough or just- just clearing, but it doesn't seem like a cold type of cough, it's a clearing of their throat."

While many respondents engaged in the process of *defining symptoms by comparing themselves to others* for each of the ATSQ items, the way that they defined the symptoms varied depending on the symptom that was being asked about. For example, smokers were most commonly used as a reference group to define the symptoms of cough and phlegm, but were less frequently associated with the symptoms of wheeze and breathlessness. Whereas, people who were overweight or out-of-shape were referred to when respondents illustrated how they were defining the symptom of shortness of breath but never for symptoms of cough or phlegm.

The process of *comparing themselves with others* in order to define ATSQ symptoms is intricately tied to perceptions of what it means to be a “usual cougher”, for example. This concept is discussed in the forthcoming section on *integrating* in this chapter. *Comparing oneself to others* is also closely linked with *understanding the research goal* as many respondents, by defining types of people who experienced the symptom in question, were also establishing their understanding of the types of people that researchers were attempting to identify through positive responses to the ATSQ questions.

### **Understanding the Research Goal**

Respondents’ interpretations of questions also were influenced by their understanding of the overall goal of the research project. Although my study and the Coastal Marine Transportation Workers Study were not explicitly delineated as lung health studies on the consent forms, the Coastal Marine Transportation Workers Study is advertised to participants as the UBC Lung Health Study. Furthermore, many of the physical tests (e.g., spirometry, chest x-ray) and the layout and focus of the symptom questions led respondents to understand that the goal of the ATSQ questions (and hence the Coastal Marine Transportation Workers and my research projects) was to assess the lung health status of participants, and to link this to potential occupational exposures. In this context, the ATSQ questions were interpreted by respondents as having been designed to detect people with respiratory disease. For example, when asked if she knew of anybody in her life that experienced the symptom of wheeze, Wendy stated: “I...can’t think of anybody in my immediate circle of friend [sic] and family that suffers from any sort of, chronic, respiratory malaise.” To her, the question, “Does your chest ever sound

wheezy or whistling?” did not simply refer to an occasional noticing of wheeze, but rather it referred to a serious sign of “respiratory malaise.” Another example from Kevin showed how he interpreted the skip patterns within the questionnaire as being indicative of the goal of doing a lung health study:

“We know it’s a lung study right? [...] So obviously they’re looking for lung problems [...]. You are looking for symptoms. You say yes then they are going to go, “Okay now he’s got symptoms now where do we go from here?” Some of them, I might have checked, “No” so if [sic] he skips the whole page.”

Even the question, “Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill?” which could literally be interpreted as an occasional occurrence, was frequently interpreted within the context of detecting people with lung disease. This may have resulted from the order in which the questions are presented, where shortness of breath is the last of the ATSQ questions to be asked of respondents (therefore it might be interpreted within the context of the prior questions).

The process of interpreting the ATSQ questions according to what “types” of people the researchers were attempting to identify sets the stage for the tensions that some respondents experienced between the symptoms that they remembered having noticed (based on literal interpretations of questions) and the “type” of person they felt that they represented (i.e., healthy vs. non-healthy, smoker vs. non-smoker). This appeared to be especially relevant for respondents who considered themselves to be free of lung disease, but who recalled having experienced the ATSQ symptoms in a way that matched their literal interpretations of the ATSQ questions.

## **V. Reflexive Noticing**

Once respondents had interpreted the ATSQ question that was posed, they began the process of deciding how they should respond. *Reflexive noticing* refers to the process

that respondents engaged in to recall if they had previously noticed a symptom. They engaged in this process based on their prior literal and intuitive *interpretations* of the ATSQ questions. For example, Sylvia talked about how her interpretation of the question led her to look back at how often she had noticed experiencing the symptom of cough: "Yeah that's right because it's not *usual* but you're thinking, "Well, I don't know. Do I do it everyday? I don't know." You know?" This process of *reflexive noticing* ranged from extremely quick and simplistic re-call to a more involved attempts to remember whether they had noticed experiencing an ATSQ symptom.

The complexity of the *reflexive noticing* process depended on respondents' *interpretations of questions* and on their prior *symptom perceptions*. Wendy, a woman in her late fifties who had started having children in her mid-forties, described struggling for years with health issues due to the stress of raising her children. She said she had later taken control of her health by starting a regimen of vitamins and minerals. She attributed this regimen with improving her health and now defines herself as very healthy. The following quote illustrates how her self-identity as healthy led her to engage in a less detailed *reflexive noticing* process in response to the question, "Do you usually have a cough?" Wendy said:

"I... was thinking about how grateful I am for being in such wonderful, good health, [laughing] [...] I never have coughs. Don't go there. Don't do that."

Other respondents who saw themselves as having a lung disease (usually those who had received a prior diagnosis) also truncated their *reflexive noticing* process by relying on their diagnosis, rather than recalling their experiences with symptoms.

Some respondents, however, were less certain about how to define themselves according to the question being asked, as illustrated by Francine:

“Yeah and ah, and like some people are very, very super healthy they never get colds or anything so they can just go bingo like that. But when you know you’ve had it you have to stop and think to yourself for a second, “Ok was it just because of that cold or was I doing it otherwise?” Or you know, no. Then you have to really define it in your mind type of thing.”

This seemed to be more common among people who had not previously formed a strong self-identity as healthy or unhealthy: “It was something I didn’t really think about until the question was asked to me” (Adam). Therefore, prior encoding of the symptom perception process combined with the intuitive interpretations of questions influenced the degree to which a respondent engaged in the process of *reflexive noticing*.

As well, it became apparent that during the *reflexive noticing* stage, respondents were not using a standardized recall timeframe. For the questions on cough, phlegm, and shortness of breath, where no specific recall periods are denoted in the questions, respondents discussed having reviewed diverse time periods ranging from their life-history through to their current experiences with symptoms. One respondent, Dean, relied on different time periods for the question of cough (3-4 years) as compared to the question of shortness of breath (5-10 years)<sup>22</sup>. For some respondents, the time period they used was correlated with the length of time they had remembered having or being free from the symptom in question; however, others did not specify a reason for the timeframe they had used.

### **Situating**

A method through which respondents recalled noticing symptoms was by *situating*; a process where respondents reviewed situations and circumstances where they may have noticed experiencing a symptom (see Table 4.4 below). Situating involved

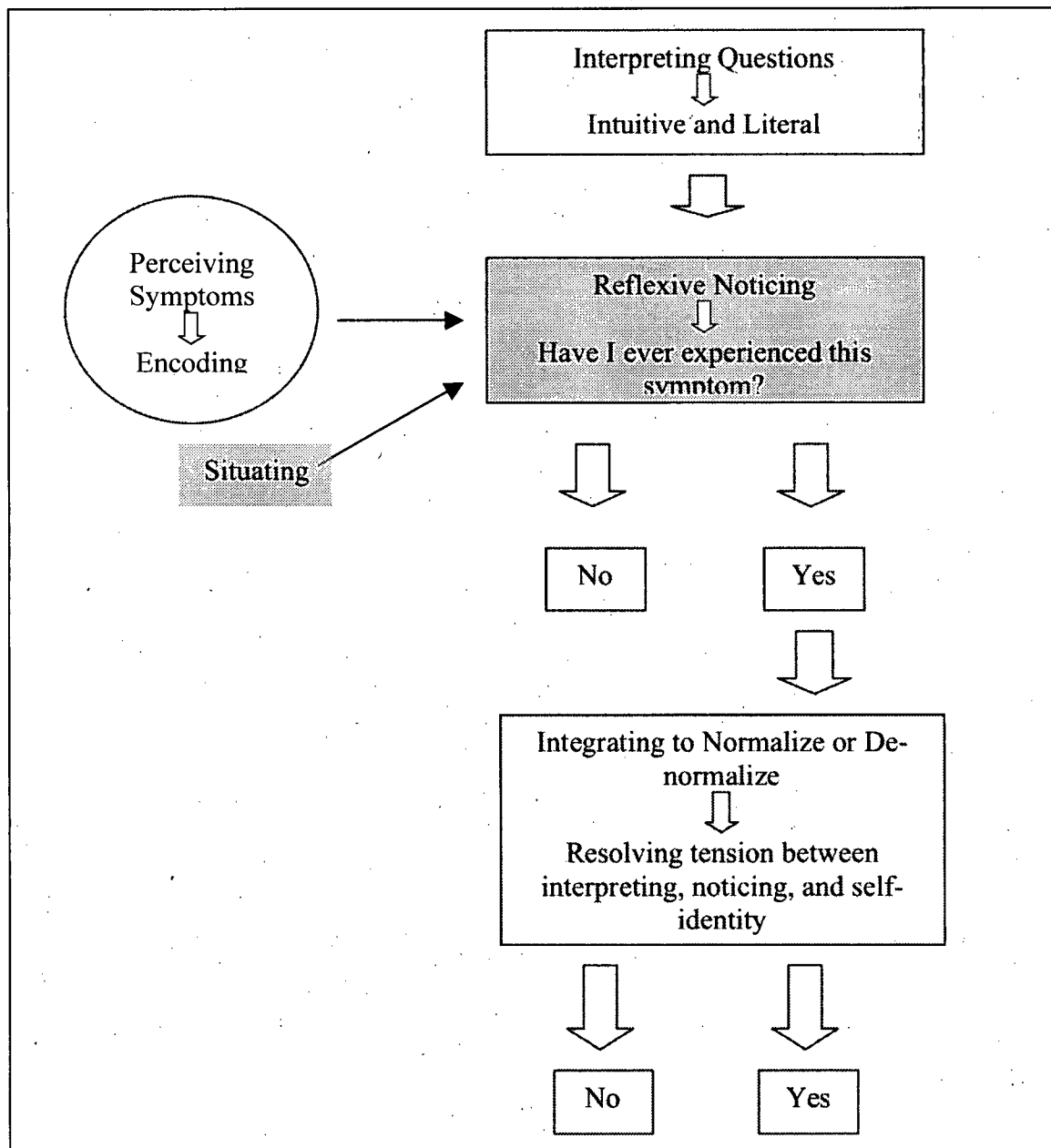
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<sup>22</sup> Dean responded affirmatively to the question of usual cough during the day/night and negatively to the question on shortness of breath (see Appendix A).



reviewing different circumstances and scenarios where a respondent might have experienced the symptom in question. This process was based on the literal interpretations of questions that respondents had previously formed, often with reliance on question triggers that helped them to determine what situations to review.

**Figure 4.4: Reflexive Noticing Stage of Emergent Conceptual Model**



The symptoms of cough, phlegm and breathlessness were most frequently referred to during descriptions of situating. Cough and phlegm had almost always been previously experienced by respondents at some point in their lives (e.g., when they had a cold). When answering questions about cough and phlegm, many respondents reflected on situations where they had had a cold in order to remember the experience of the symptom of cough and to determine if their memory of noticing the symptom fit with their current interpretations of the question and research goal. Adam discusses his struggle to remember whether he experienced a cough on a "usual" basis:

"Yeah, you just start thinking about it. It's something you don't really think about, "Ok, yeah, I cough when I have a cold," and then you start thinking about it, "No I didn't have a cold."

For the question, "In the past 12 months, have you had periods or episodes of cough with phlegm that lasted one week or longer?" respondents frequently discussed struggling to recall if their symptoms had lasted one week or longer. Many respondents initially recalled that their symptoms of cough and phlegm had not lasted for one week or longer, but some reconsidered upon further reflection during their follow-up interview with me.

For the symptoms of cough and phlegm, respondents discussed noticing symptoms when they were in a sick environment. Men in particular discussed their reactions to acute exposures that led to coughing or bringing up phlegm to clear their lungs: "Because I mean if you're working and you get a shot of dust or something, so you know yeah, I may be coughing for a minute or so but then I'll try to clear it out" (James). Frank also discussed his sick environment at work as a situation where he noticed a wheezing or whistling chest: "If I get overdosed with dust and that sort of thing then my lungs seem to feel like they're filling up and so it's harder to breathe so if I do get a dose

of that then I really have a more laboured breathing” (Frank). The gendered nature of this finding will be discussed in the section, Gendered Social Roles.

When engaging in *reflexive noticing* of shortness of breath (and sometimes wheeze), most respondents reviewed situations where they had engaged in exercise or other types of exertion (e.g., climbing stairs, lifting heavy objects). As Gary said:

“Well the only time I’m short of breath is...like I was, believe or not, running around, [...], playing rugby last Sunday. [...]. And there was four over 60 guys playing last week. And we’re playing this Sunday again at [place] and Wednesday. And I guess I do feel out of breath. After I run around the track, I get short of breath. But I’m not gasping for breath when I walk up a set of stairs.”

Exercise situations were also reviewed by respondents who did not recall experiencing any symptoms, as Wendy’s story illustrated: “I thought of all the physical activity I do and how easily I do it, without any of those sorts of symptoms.”

Respondents engaged in varying levels of *reflexive noticing* depending on how certain or uncertain they were regarding their prior perceiving of symptoms. Respondents who were uncertain about how to define their health in relation to their interpretations of the ATSQ symptoms used the *reflexive noticing* process to assess the degree to which they had ever experienced the symptom in question. After they had engaged in this process of *reflexive noticing*, they then began the process of determining whether the symptom that they noticed matched their *interpretations* of the questions.

## **VI. Integrating to Normalize or De-normalize**

*Integrating* refers to bringing together the processes of *interpreting the question* and *reflexive noticing* in order to formulate responses to the ATSQ questions. *Integrating* led respondents to either *normalize* or *de-normalize* their symptom experience. The ease with which respondents discussed *integrating to normalize or de-normalize* was influenced by their prior *perception of symptoms* and the resultant encoding. In addition,

*integrating* was influenced by respondents' attempts to align their literal and intuitive *interpretations of questions*. Hence, respondents who had previously received a medical diagnosis (or those who clearly defined themselves as healthy) easily matched their *interpretations of questions* with their *reflexive noticing* processes to formulate a response during the *integrating* phase. In addition, it appeared that some respondents did not form intuitive interpretations of questions and therefore did not struggle to align their self-definition of their respiratory health status (based on intuitive interpretations of questions) with their *reflexive noticing* of ATSQ symptoms (often based on more literal interpretations of questions). Instead, these respondents simply formulated a response based on whether they had experienced the symptom in question (e.g., did they experience shortness of breath when walking up a slight hill?).

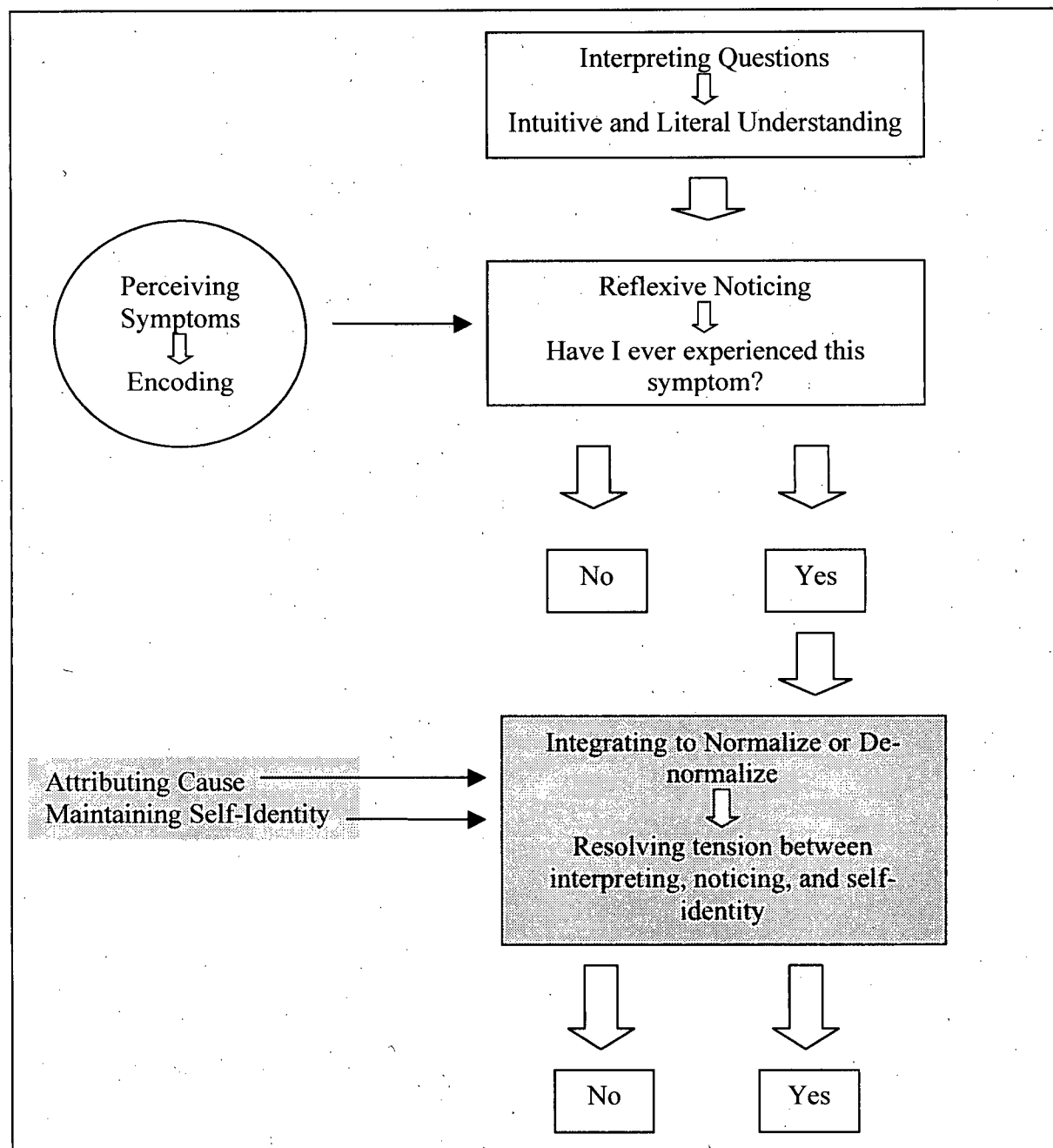
Other respondents struggled to determine whether the symptoms that they noticed might be considered normal within the research context and many respondents even reformulated their original responses upon further reflection during my interviews. This was most often the case among respondents who recalled having noticed symptoms, but did not feel that they were the *type* of person that the ATSQ was attempting to identify (i.e., they did not feel that their symptoms reflected a chronic lung concern). Respondents who had not previously engaged in the process of *perceiving symptoms* struggled to *integrate* their response processes. For these respondents, the *integrating* process was challenging because they were attempting not only to recall whether they had experienced the ATSQ symptom, but they also were attempting to do this within the context of their intuitive *interpretations of the questions*. Therefore, within the

“pressurized” research settings, respondents struggled to quickly formulate an “accurate” assessment of their lung health symptoms and their lung health status.

Although many respondents discussed experiencing similar tensions between their intuitive understandings of the questions, their *reflexive noticing* of symptoms, and their self-definition of their lung health, these tensions were *integrated* in different ways; through a similar line of reasoning, a symptom would be normalized by one respondent and de-normalized by another, or one respondent would provide similar descriptions of both cough and phlegm but would normalize one and de-normalize the other.

Respondents also discussed disparities in response patterns amongst the various “waves” of the Coastal Marine Transportation Workers study as well as differences between their responses on the current Coastal Marine Transportation Workers initial interview and the reports they provided during my follow-up interview. Normalizing or de-normalizing the symptom was dependent on respondents’ perceptions of what component was most important: (a) their *reflexive noticing* of symptoms or (b) their self-definition of their lung health given their intuitive *interpretations of the questions*. Throughout the following sections, respondents’ quotes illustrate the potentially conflicting patterns of response. However, central to all of these quotes is respondents’ treatment of the integration processes through which they *attribute cause* and *maintain their self-identity* in order to formulate a decision about the normal or abnormal nature of the symptoms they recalled having experienced (see Figure 4.5 below).

**Figure 4.5: Integrating Stage of Emergent Conceptual Model**



### Attributing Cause and Maintaining Self-Identity

Normalization and de-normalization appear to be achieved through *attributing cause* and *maintaining self-identity*. Respondents' interpretations of the cause(s) of a symptom either led them to be concerned (and hence de-normalize the noticed symptom)

or it led them to consider the symptom to be normal given their prior *interpretations* of the ATSQ questions and the context of the research goal, as the following excerpt from John's interview illustrates:

"... well there is a thing that clouds the issue a little bit, because I take three medications for heart trouble and one for high blood pressure has the tendency to give people a cough. So, it kind of complicates the answer, you know. [...] Umm...the cough that is not related to lung problems, you know, so I'm not sure about that" (John).

John had responded, "No" to the question, "Do you usually have a cough?" because he believed that the cough he noticed was caused by his heart medication (i.e., *attributing cause*) and, therefore, was not the result of a lung health problem (i.e., it was normal for someone taking that medication to experience cough). Conversely, many respondents de-normalized symptoms because they found the cause of the symptom to be concerning and possibly associated with negative lung health consequences.

The process of *attributing cause* was repeatedly associated with *situating*. Once a respondent had reflected on the situations in which they had noticed their symptoms, they considered the cause of the symptom (e.g., is the symptom due to exercise, being ill, or being exposed to something in the environment?). For example, many respondents situated their symptoms within the context of physical activity or exercise (particularly for the symptom of shortness of breath) and drew on these situations to either normalize or de-normalize their symptom based on the cause of the situation (i.e., the physical exertion). The following quote by Heather illustrates the complex and conflicting nature of this integrating process:

"It was just going up a couple flights of stairs. I would be so out of breath and [sighs] and I thought what's with this cause I'm fairly active so, I had to think about no, I'm always in a hurry and I'm not short of breath there but..."

In this instance, Heather believed that her symptom was normal as it was caused by her hurrying up stairs and did not happen at other times. However, Heather later reconsidered her answer to the question on shortness of breath because she recalled that she also experienced shortness of breath when she was walking up hills:

“It just seems to be that incline I’m thinking “What’s wrong with me?” You know, walking in Vancouver I’m going “This hill is killing me” I’m going, “Something’s not right here.””

Heather, a non-smoker who considered herself to be highly physically active, identified as a very healthy person. This may have led to her initial normalized response to the ATSQ shortness of breath question. However, when she further considered her experiences with shortness of breath, she decided that her noticing of breathlessness was abnormal given her usual level of athletic ability. Here, the conflict between *self-identity*, *reflexive noticing*, and *intuitive interpretations of questions* is clearly illustrated and shows how the uncertainty that Heather experienced led her to change her response choice between the Coastal Marine Transportation Workers interview and my follow-up interview.

Symptoms also were normalized if they were attributable to poor physical fitness (i.e., something that could be changed vs. an irreversible lung condition) as described by Kevin:

*Kevin:* So I wouldn’t, you know I might have shortness of breath but I can attribute it to something else. [*Interviewer:* And because it is not about your lung health]

*Kevin:* Yeah, I wouldn’t suspect my lungs are, well if I were to suspect my lungs I would suspect it’s because I’m out of shape.”

Therefore, respondents’ understanding of the research goal and self-identity as physically fit (versus unfit) influenced the process of integrating and led respondents to normalize or de-normalize their symptoms accordingly.



Respondents also used comparisons to themselves in a sick-state to normalize or de-normalize the symptom they experienced, as illustrated by Isabelle:

“The only time that I bring out phlegm is if I’ve got a full blown cold. And then it’s just a clearing and it’s over and done with, but on a non-sick basis, no. It never happens.”

Respondents used comparisons to themselves in a sick-state to define what would be abnormal and then contrasted that sick-state with what they experienced on a regular basis in order to normalize their experience with the symptom. Because their symptom only occurred as the result of an acute illness, the symptom was normalized. This strategy was most likely to be used by respondents whose discussions of their symptom experience suggested that they rarely experienced symptoms. Therefore, those who used comparisons to themselves in a sick-state to identify the cause of their symptom, rarely experienced tension between their interpretations of questions, their reflexive noticing process and their self-identity as healthy.

A number of respondents discussed normalizing a symptom because they perceived it to be the result of an exposure (i.e., sick-environment), as was the case for James, who said:

“... that would be what you are exposed to, right? I mean if you are breathing in bloody exhaust because these idiots are running their machines while you’re working, yeah you’re going to be coughin trying to get that crap out. But as a rule no.”

While it may seem more logical to de-normalize symptoms resulting from an exposure, especially exposures which have been linked to lung disease, some of the respondents did not make this connection. Respondents who were exposed to dust, fumes or other airborne contaminants in work environments often perceived symptoms as being “part of the job.” They also tended to view the exposure as being more acute (e.g., they received a

blast of dust) and therefore may perceive the resulting symptoms as a more temporary condition:

“Plus you say *usually*, I mean, you know, everybody coughs to clear your lungs or whatever. And that also has to do with your environment, what we’re doing, who’s doing what next to you. I mean, we can set ourselves up as safe as we want and then they’ll come up and put a piece of tape this wide [illustrates barrier with his fingers] as a barrier and you’ll have a guy sawing next to you. Yeah, that’s going to magically stop everything that piece of tape right? You know? Come on.” (James).

Kevin described how the use of protective respiratory gear is not always possible: “My other concern is that we’re exposed to stuff here right, and we don’t always have a chance, we don’t always have our respirators and don’t always have protection so.” Therefore, exposure at work was often viewed as temporary and beyond individual control.

Many of the respondents who discussed their symptoms as resulting from workplace exposures struggled with the process of integrating to normalize or de-normalize. Both James and Kevin discussed their symptoms of cough and phlegm as resulting from exposures at work. However, the following quote from Kevin’s discussion of his experience with the symptom of phlegm illustrates how he struggled to integrate his reflexive noticing of phlegm in his work environment, with his self-identity as healthy:

“I don’t know if it’s coming from. Like I don’t cough it like I’m sure that there is people that have respiratory problems that [cough] and it comes up. You know I was, I find that I have a lot of phlegm. Not associating it with a lung problem just thinking that ah it’s just the stuff I am breathing in or something that is just accumulating and spitting itself out.”

Although Kevin perceived that the question was attempting to identify people with respiratory disease (which he did *not* feel that he experienced), he felt that his reflexive *noticing* of phlegm at work, matched the literal *interpretation* of the ATSQ question and

therefore, responded affirmatively. James also discussed his reasoning for both usual cough and usual phlegm in a similar manner, stating that he experienced both of these symptoms as the result of exposures at work; however, he responded affirmatively to usual phlegm and negatively to usual cough. Inconsistent *integration* processes (similar to that described by James for the symptoms of cough vs. phlegm), were similarly described by other respondents for these symptoms and for the symptoms of wheeze vs. breathlessness.

In some cases, *not* recognizing a reasonable cause for a symptom (e.g., being a smoker) was itself a cause for concern. Adam, who struggled to form a response to the question, "Do you usually have a cough?", discussed how not being able to find a cause for his symptom was what led him to de-normalize his morning cough: "Yeah. But I've been thinking about it and maybe I should say *yes* because sometimes I wake up in the morning and I cough my lungs out a little bit for no particular reason." (Adam). He also stated that it was almost like he was a smoker, even though he had never smoked, which may have caused Adam to worry about the possibility that he could have a lung disease. Through this type of discussion, Adam and others illustrated that during the integrating phase, respondents were attempting to find reasons why symptoms they experienced were either normal or abnormal in order to formulate their reporting decisions.

Respondents' language use also reflected their perceptions that to describe having a lung disease was to have something "wrong" with you and that having numerous symptoms was "weird" or "abnormal." For example, Dean indicated that he responded "no" to the question on usual cough because: "I know for a fact that *physically* there's nothing wrong with me; it's sinus related." (Dean). His response includes two

components that may help explain his de-normalizing process. First, he indicated that there was nothing “wrong” with his lungs (claiming that his symptom was sinus related) and therefore what he experienced was not relevant to the question. Second, his quote illustrates how admitting that you have symptoms is also admitting that you have something wrong with you. Dean also discussed how having more broadly defined response categories, such as “yes,” “no,” and “other” (as compared to the current yes/no format) would decrease the pressure of having to define oneself as, for example, a chronic cougher. Bertha also described how many people do not want to admit that there is something wrong with them:

“I like to think that that I’m healthy, I’m fine. And I think everybody does. Or most people do.”

## **VII. Femininities and Masculinities**

Respondents’ perceptions about femininities and masculinities affected their responses to the ATSQ, particularly with reference to the item about phlegm. During my interviews, respondents (both men and women) attempted to locate themselves in terms of their own sense of how femininities and masculinities might affect their self-reports of health (or ill health). For example, James presented himself as “old school” when it came to gender expectations about reporting illness. He suggested that men would deny illness at all costs: “You don’t go to the doctor unless your leg is actually falling off.” This quote is interesting because it illustrates how James’ perceptions of masculinity influenced his need to portray a highly masculinized self-identity during our interview. He presented himself as an outdoorsy man and frequently made jokes throughout the interview. Moreover, James’ denial of experiencing most symptoms (although he did report phlegm)

was also a tool for maintaining his stereotypical sense of what constitutes a man who is strong and healthy. While this was also true for some of the other men, many also indicated that they did not feel that norms of masculinity would influence responses. Of all the symptoms (cough, breathlessness, wheeze, phlegm), the act of reporting phlegm was viewed as being the least threatening to men's sense of masculinity. Reporting breathlessness, wheeze and cough were all associated with weakness and/or ill health, which was viewed to be somewhat emasculating.

Women and most men suggested that admitting to experiencing phlegm was extremely unfeminine. Women more often described phlegm as "gross;" they also were more likely to describe never having been able to bring up phlegm, even if they could feel the phlegm in their chest. No men discussed this phenomenon of suppressing phlegm. Many women and men in my study discussed the fact that spitting is a learned habit for men and that women are taught and/or conditioned to never bring up phlegm, even if they have it.

In general, women described phlegm in very negative terms. For example, Patty described how she had tried to discipline her grandson about bringing up phlegm:

"I know, I say, 'Quit doing that! It's not very nice. It makes grandma sick to see you do that'. [And her grandson replied:] 'Grandma, it's a man thing. Live with it.'"

This quote also illustrates how the act of bringing up phlegm is perceived in highly masculine ways. Like most women in my study, Sylvia expressed disgust at the thought of bringing up phlegm:

"No, because I mean *phlegm*, it's [inaudible] and I'm definitely not bringing *that* up... Yeah, like I do *not* definitely do that."

When I asked men if they thought there was a gender difference in reporting the symptom of phlegm, many of them asked me (sometimes sarcastically) if I'd ever seen a woman bring up phlegm (and spit it out), because they had not.

### **VIII. Gendered Social Roles**

Some of the male respondents talked about their work environment and exposures (to dust and fumes) as leading to the need to "clear out" their throats and/or lungs. This was less noticeable among the women (who primarily worked in office and kitchen environments), although a couple of women did talk about air conditioning causing tickles in their throats or other forms of minor irritation. In my sample, more men than women were employed in physical labour jobs such as ship maintenance and engineering. In particular, some of the men who worked at the shipyard discussed being aware of exposures that they believed were causing their symptoms (e.g., wood dust and welding fumes).

Men also talked about how their work culture (in comparison to women's work culture) was more conducive to experiencing certain respiratory symptoms, especially phlegm. The work culture and environment did not prohibit men from coughing loudly or bringing up phlegm and spitting it out: "I've been working for a long time in this type of an environment where, it's pretty rough around here so nobody thinks twice about that sort of stuff" (Frank). One male participant talked about how if there were more women in these work environments, then it might become more common and acceptable to see women bringing up phlegm:

"Well, it's just the way they are right. I mean unless you got some women welders like these I mean it probably wouldn't bother them" (Kevin).

He explained that this difference was the result of social expectations of behaviour in traditionally feminine workplaces:

“So it’s their workplace, right, they are dealing with the public or something and we’re dealing with a piece of wood or some steel or something so it doesn’t talk back to you. You don’t have to be polite.” (Kevin).

A female participant also made the distinction between levels of masculine acceptability of certain symptoms among males in traditionally masculine jobs. She suggested that bridge workers would be even less concerned about the social acceptability of their symptoms than the men working in the shipyard. Nancy described her co-workers at the shipyard as “normal, married guys,” while other construction workers (she referred to bridge builders) were perceived to be more rough and tough.

The few women that I interviewed who worked in traditionally masculine occupations (e.g., painter; deck hand) said that they were not expected to become “one of the boys” by engaging in spitting. One female painter described her experiences on the outside of the “boys club” looking in:

“Well, they’re outside in their area, they don’t think I’m going to come around the back because I sit out there and read. So, I know who spits [laughs]” (Nancy).

For Nancy, it was not acceptable for her to join in the masculine behaviours of spitting phlegm and she noted that the men would apologize once they noticed that she had observed them spitting phlegm.

## **IX. Lay Theories of Gender and Health**

Many respondents discussed their lay theories regarding the influence of gender on experiencing and reporting on the ATSQ questions. While it is difficult to identify if and how these theories influenced respondents’ actual responses to the ATSQ questions, the dialogues regarding lay gender theories indicated that people frequently held distinct

views of men's and women's health behaviour. The most common lay theories were: (1) women are more likely to notice symptoms because of their role as family caregiver; (2) women are too busy to get sick because of their roles as family caregiver; (3) men don't notice or admit to symptoms because this would be seen as a sign of weakness; and (4) specific symptoms (e.g., cough and phlegm) are not 'lady-like,' while shortness of breath is 'unmanly.' However, there were also many respondents who indicated that they did not believe that gender differences would exist between men's and women's experiences and/or reports of symptoms. Some of the women had strong negative reactions to my questions regarding potential gender differences in reporting of symptoms.

## **X. Conclusion**

This chapter presented an emergent cognitive model that described how respondents *interpreted* ATSQ questions, *reflexively* noticed ATSQ symptoms, and integrated their interpretations and experiences to formulate a response. Respondents who clearly defined themselves as healthy or unhealthy with regard to ATSQ symptoms easily formulated their responses, while respondents who experienced tension between their *interpretations*, *reflexive noticing*, and *self-identity* struggled to provide their responses. While the response processes were similar for men and women, gendered work environments and the masculine nature of expectorating phlegm differentially influenced men's and women's responses. The next chapter discusses the implications of the tensions experienced by respondents and the gender influences on men's and women's responses within the context of the goals of the ATSQ.



## CHAPTER FIVE: DISCUSSION

The nascent model that emerged from this study, including the key stages that appear to have influenced response outcomes (i.e., *perceiving symptoms, interpreting questions, reflexive noticing, and integrating*), reflects many of the findings that have been described in previous research on the Cognitive Aspects of Survey Methodology (CASM) [33, 34, 36-39]. However, the model that was articulated based on data gathered from the current study specifically pertains to the cognitive processes involved in reporting symptoms of respiratory disease using the American Thoracic Society Questionnaire (ATSQ) (which has not been previously studied). Based on the findings from the current study and drawing upon previous work, I will discuss the potential relevance of the emergent theoretical model as a framework that has unique qualities pertaining to self-reporting of respiratory symptoms on the ATSQ, as well as make suggestions that could be beneficial to the design, administration and interpretation of the ATSQ in the future.

### **I. Gender Related Psychosocial Factors Affecting Men's and Women's Responses to the ATSQ**

Research on cognitive aspects of survey methodology has yet to focus extensively on gender [36, 68]. Specific to the reporting of respiratory symptoms, Kauffman and Becklake [3, 12] have suggested that hegemonic forms of masculinity and femininity may influence the reporting of phlegm and breathlessness. In the current study, men and women generally engaged in similar cognitive processes when responding to ATSQ questions. While the gender and health literature indicates higher overall rates of morbidity among women (resulting from socio-economic inequality, stress from

women's social roles, and the feminine nature of the sick role) [6], these did not emerge as findings of the current study. For example, the literature suggests that stress is a major factor in women's excess reporting of morbidity [56, 59]; but, stress did not figure prominently in the current study (i.e., only a few people talked about it as a possible explanation for gender differences in symptom reporting).

However, two gender differences were noted in this study. Not surprisingly given Kauffmann and Becklake's prior findings, the reporting of phlegm emerged as a symptom that appeared to be more highly stigmatized for women as compared to men. In addition, the masculinization of the act of bringing up phlegm (and spitting it out) appears to extend beyond simply reporting the symptom, to experiencing the symptom in day-to-day life. Women in the current study reported that even if they could feel phlegm in their chest, they did not know how to expectorate phlegm and/or did not feel that it was appropriate for a woman to spit out phlegm. The masculinization of the symptom of phlegm appears to be re-enforced by differences in men's and women's work environments (at least within the context of the Coastal Marine Transportation Workers population). More men were working in jobs that did not require interaction with the public and hence did not place social restrictions on the act of expectorating phlegm.

In the current study, men also were more likely to describe their symptoms as being "just a part of the job," particularly if they felt that it was not always possible to adequately protect themselves from detrimental exposures. While women in this sample did not discuss work exposures as causing their ATSQ symptoms, there is an emerging body of research that is beginning to document occupational exposures (e.g., cleaning

substances, poor air quality/ventilation, photocopy toner) that may be linked to respiratory disease among female workers [92].

Although the current study is exploratory in nature (and therefore does not claim to have captured all gendered concepts related to the self-reporting of respiratory symptoms), the findings highlight how gender as a social concept may exert unique influences in diverse areas of health and illness. Furthermore, higher rates of self-reported dyspnea have also been consistently found in the respiratory health literature and a gendered explanation (as well as possible biological or sex explanations) had been proposed by Kauffmann and Becklake [3]. The findings from the current study did not support a gendered explanation for observed differences in the reporting of dyspnea.

## **II. Potential Implications of Self-Reported Cognitive Processes for the Design, Administration, and Analysis of the ATSQ**

Before launching into a more detailed discussion regarding the ways in which my data may help inform the evolution of design, administrative and analytical features of the ATSQ, three more overarching comments are important to understanding the use of the ATSQ as a tool designed to gather self-report symptoms. First, the ATSQ is designed to achieve a high level of specificity<sup>23</sup> through the following directive: "If you are in doubt whether the answer is yes or no, please answer no." In respondents' discussions during this study, it appears that many people struggled to decide whether or not the symptom that they experienced was significant to report and responded inconsistently to

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<sup>23</sup> Specificity is the proportion of truly nondiseased persons who are so identified by the questionnaire (note: although the term specificity usually applies to a screening test, the ATSQ is not used as a screening test).

these instructions. These inconsistencies will be discussed in relation to the effects on specificity and sensitivity<sup>24</sup> and suggestions for potential improvements will be made.

Second, the ATSQ has traditionally been used not only as a measure of symptom prevalence, but also as a measure of disease prevalence in population and occupational health research, using symptom complexes as indicators of COPD and asthma (e.g., chronic cough and phlegm for COPD and wheeze/breathlessness for asthma). While there is a consistent correlation between symptoms and lung disease, it is often modest [89, 100, 101]. Among the sample in the current study (a sample comprised primarily of working people), most of the respondents *did not* have lung function measures that were indicative of COPD and only five respondents had been diagnosed with asthma. However, despite their relatively high levels of lung function (and low levels of disease) many people responded affirmatively to one or more of the ATSQ questions<sup>25</sup>. Perhaps what this finding speaks to is the notion that the ATSQ, when used amongst relatively healthy populations, is better at tapping into *risks* of developing lung disease, rather than capturing data related to *diagnosed* lung disease (as constituted by measures of physical functioning): The intended purpose of the questionnaire has significant implications for the analysis of symptom data. As discussed below, two different concepts can be collected using symptom data and the way that they are analyzed and their correlation with the development of lung disease should be explored in more depth to assess the usefulness of each concept.

Third, based on my data, I would suggest that two distinct concepts are being operationalized within many of the ATSQ questions, respondents': (1) "objective"

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<sup>24</sup> Sensitivity is the proportion of truly disease persons in the sample population who are identified as diseased by the questionnaire.

<sup>25</sup> This is at odds with the stated goal of achieving high specificity.

experiences of respiratory symptoms (i.e., the symptoms they recalled having experienced) and (2) self-assessments of the importance of these symptoms as markers of poor lung health. While both of these concepts may be important factors in predicting negative lung health outcomes, results from the current study indicate that some respondents struggled to integrate these two processes to formulate a response. Revising the ATSQ questions to allow respondents to separately report their “objective” symptom experience and, then in different sets of questions, tap into the significance of these symptoms, may help to mitigate the tensions experienced by respondents. The following table provides a summary of the major processes that were identified during my analysis and suggestions for revising the ATSQ. Each implication, for the processes outlined in the table below, is expanded in the paragraphs following Table 1 (e.g., process A, implication 1 is denoted as implication A.1).

**Table 5.1: Summary of Key Findings and Potential Revisions for the ATSQ:**

<b>Process</b>	<b>Potential Revisions for the ATSQ</b>
<b>A. Interpreting Questions:</b> Questions led respondents to form both literal and intuitive interpretations. Inconsistencies in interpretations were noted.	<ol style="list-style-type: none"> <li>1) Provide explicit definitions of the terms used in the questions and response options. See A.1 below.</li> <li>2) Develop questions which allow respondents to provide a self-assessment of the significance of their reported symptom. See A.2 below.</li> </ol>
<b>B. Reflexive Noticing:</b> Respondents used cues to help them remember noticing/not noticing symptoms.	<ol style="list-style-type: none"> <li>1) Provide situational cues to stimulate respondents' recall of symptoms. See B.1 below.</li> </ol>
<b>C. Integrating:</b> Respondents normalized/de-normalized their symptoms depending on their reliance on either literal or intuitive interpretations of ATSQ questions.	<ol style="list-style-type: none"> <li>1) The suggestions provided for potential revision A.1 and A.2 may address this process.</li> <li>2) Provide instructions to respondents asking them to report their experience with symptoms in the initial questions and their assessment of the significance of these symptoms in the follow-up questions. See C.1 below.</li> </ol>

**Potential Revision A.1 *Provide explicit definitions of the terms used in the questions and response options.***

The use of vague concepts/quantifiers has previously been defined as problematic in the literature on survey design, as it can lead to differences in respondents' interpretations and, therefore, their responses [41]. Groves et al. [33] recommend providing concrete definitions of terms in the root of the question and providing a sufficiently diverse range of response options that reflect the broad ranging nature of many symptoms. This kind of approach may also help limit respondent reliance on intuitive interpretations and help respondents to focus on the literal interpretation.

While creating more defined questions could potentially aide those respondents who felt they did experience symptoms but did not think that their symptoms were the result of lung disease (i.e., improve sensitivity), it may also offer more standardized definitions to respondents who reported symptoms based on experiences that researchers may not consider to be indicative of a chronic symptom (i.e., enhance specificity). This may be particularly true for the seemingly problematic question of shortness of breath where many respondents described having responded affirmatively because of seemingly "normal," exercise-induced shortness of breath (e.g., after running up a flight of stairs). At the very least, it is recommended that the standardized probes on the ATSQ be asked of all respondents and not just those who ask for further clarification (e.g., the probe, "exclude clearing of the throat" (see Appendix B for full ATSQ). As well, the use of categorical response options could allow for responses to be analyzed to reveal potential trends or gradients in the experience of symptoms (although they also can easily be recoded to dichotomous outcomes where appropriate). Other research regarding

respondents' attempts to decipher the intended meaning of questions (i.e., what information the researcher is truly attempting to garner) also indicates that more precisely defined questions and response options are helpful in reducing respondent reliance on intuitive interpretations [42, 44]. However, any future revisions should be tested against the current ATSQ to determine validity and reliability (see IV. Recommendations for Future Research).

**Potential Revision A.2: *Develop questions that allow respondents to provide a self-assessment of the significance of their reported symptom.***

When respondents simultaneously formed both literal and intuitive interpretations of questions tensions often arose between their experiences with symptoms and their perceptions of their lung health. Because respondents' self-assessments of their health status have been found to offer excellent predictors of future health/disease outcomes (e.g., the development of lung disease or mortality) [102], it may be useful to add questions that allow respondents to provide self-assessments of the significance of their ATSQ symptoms. Developing separate questions to tap into literal versus intuitive assessments of symptoms might help to reduce the tension experienced when reporting symptoms on the current ATSQ, while allowing researchers to assess the relationship between symptoms and respondents' conceptualizations of lung disease.

**Potential Revision B.1: *Provide situational cues to stimulate respondents' recall of symptoms.***

The ATSQ questions do not include situational cues to help respondents recall symptoms (with the exception of the question on shortness of breath, which refers to hurrying on level ground or walking up a slight hill). Prior research has suggested that

surveys can use retrieval cues or question triggers to help respondents understand the types of situations and memories that they need to review in order to determine their response [33]. Revising questions to provide the respondent with situational cues could assist with symptom recall. Additionally, this revision could help researchers determine whether a respondent's cough occurs in multiple situations, which might be indicative of a chronic cough that could be distinguished from an acute episode of coughing. However, situational cues need to be designed so as not to limit the range of circumstances and scenarios that are brought to mind by respondents.

**Potential Revision C.1: *Use explicit definitions and allow respondents to provide self-assessments.***

When respondents normalized or de-normalized symptoms, they failed to consistently apply their literal versus intuitive interpretations of questions. A respondent could reply to one question using a literal interpretation, while replying to another based on an intuitive interpretation. Developing separate questions to tap into literal versus intuitive assessments of symptoms might help to improve the consistency with which respondents apply either literal or intuitive parameters (see Revisions A.1 and A.2). It may also be beneficial to provide instructions to respondents that guide them through this response process and inform them of the different response expectations for each set of questions. However, if any potential revisions are applied, the validity of the revised ATSQ should be tested against the current ATSQ to determine if the suggested revisions are in fact beneficial (see IV. Recommendations for Future Research).



### **III. Strengths and Limitations of the Current Study**

The purpose of the current study was to describe the ways that men and women interpreted and responded to ATSQ questions, and the potential gender-related psychosocial factors that may have affected their response processes. This study provided an in-depth examination of the cognitive process that men and women engaged in when responding to the ATSQ questions and highlighted the complex nature of reporting decisions. My findings suggest that the design of the ATSQ may have led respondents to integrate literal and intuitive interpretations of questions. While cognitive response patterns were also found to be similar for men and women, findings from the current study were able to identify two potential gender-related psychosocial influences on the self-reporting of respiratory symptoms.

One of the most significant limitations of this study is that it relied on retrospective reporting of cognitive and emotive response processes. Therefore, some respondents may have described their symptom reporting processes differently than they actually occurred when initially responding to the ATSQ. However, discrepancies between initial and subsequent descriptions of response processes were rich sources of data that illustrated how some aspects of the ATSQ are potentially problematic. As well, social desirability around gender equality may have affected responses to my questions about the influence of gender on symptom reporting, especially among women working in traditionally masculine job roles.

Since many of the respondents had already completed the Coastal Marine Transportation Workers study protocol prior to participating in my interview, they often expressed the desire to keep my interview short. In addition, the abstract nature of my

questioning (e.g., to many people, a cough is simply a cough) often led to some frustration. In order to minimize respondent burn-out, I kept my interviews short especially for those interviewees who expressed frustration (interviews ranged from 5-50 minutes). However, respondent burn-out may have influenced the degree to which respondents provided accurate descriptions of their cognitive response processes. Given this time constraint, I was only able to probe initial ATSQ questions for each symptom item.

The small sample size and specific characteristics of this sample limit the generalizability of this exploratory study. Moreover, while many qualitative studies strive to achieve theoretical saturation (where no new themes emerge with additional interviews), it was not feasible to achieve saturation with this sample due to time and resource constraints. In addition, given that the Coastal Marine Transportation Workers study has an occupational focus, respondents also appear to have focused on occupational experiences when discussing their response processes in this study. Therefore, it is acknowledged that many other factors may play a role in the reporting of respiratory symptoms utilizing the ATSQ.

#### **IV. Recommendations for Future Research**

In light of the findings from this study, several areas of research emerge as needing further exploration, including:

- 1) Continued testing of the validity and reliability of the 2004/05 revised ATSQ and any additional revisions.*

While the current study found that respondents often struggled to formulate accurate responses to the ATSQ questions, resulting in inconsistent response patterns,

additional validity and reliability testing should be conducted with a larger sample of respondents. Members of the Interdisciplinary Capacity Enhancements: Bridging Excellence in Respiratory disease and Gender Studies (ICEBERGS) team are currently conducting a reliability and validity study of the revised ATSQ with the following objectives:

- 1) To examine the reproducibility of self-reported ATSQ symptoms;
- 2) To examine the correlations between the revised and original ATS questionnaires with respect to: reporting of symptom frequency and severity; prevalence of COPD and asthma phenotypes (using symptom complexes); associations between symptoms, phenotypes, and objective measures of lung function;
- 3) To compare results from objectives 1 and 2 for men and women.

Findings from this ongoing study may inform the need for additional revisions (such as the ones suggested in Table 5.1) that might enhance the reliability and validity of the ATSQ. Any future revisions to the ATSQ should be pilot tested and the reliability and validity should be compared to that of the current ATSQ.

*2) Longitudinal analysis to assess whether self-reported ATSQ symptom complexes provide evidence of a person's risk for the development of measurable lung disease and assess potential gender differences in the validity of these symptom complexes.*

In occupational- and population-based respiratory epidemiological studies, symptom data is almost always collected but rarely analyzed (physical measures of airway obstruction are considered to be better prevalence measures of obstructive lung disease). While some studies have shown correlations between reported symptoms and

the development of lung disease, this is an area that is relatively under-researched, in part due to a lack of adequate analytic techniques to assess the correlation between different patterns of reporting (e.g., consistently symptomatic/asymptomatic versus incident/regressed symptoms). Currently, Victoria Arrandale, a trainee with ICEBERGS is conducting an MSc thesis on the following questions:

1. What method(s) are best suited to identify and analyze symptom patterns using the Coastal Marine Transportation Workers occupational cohort as a sample data set?
2. How do symptom patterns relate to lung function changes over time?
3. Are there gender differences in how symptom patterns relate to lung function changes over time?

Results from her thesis may inform ways to use ATSQ symptom data as measures of risk of developing measurable lung disease. Since my study findings suggest that women are less likely to report the symptom of phlegm, findings from Arrandale's thesis may identify which symptom complexes best correlate with the development of measurable lung disease amongst women as compared to men.

*3) Continue to explore the factors affecting self-reporting of respiratory symptoms.*

While research has focused extensively on the effects of smoking (and to a lesser extent, other environmental and occupational exposures) on the development of respiratory symptoms, to my knowledge no research has examined the effects of respondents' perceptions of exposures on self-reporting of respiratory symptoms. The current study suggests that smoking and occupational exposures may influence the degree to which respondents come to perceive their experiences with symptoms as significant

within a lung disease framework. It is also acknowledged that physical sex characteristics may play a role in the different descriptions of men's and women's experiences with the symptom of phlegm. Continued research on potential sex differences in the etiology and experience of lung disease is important.

## **V. Conclusion**

The current study examined the response processes that men and women engaged in when responding the ATSQ and supports the notion that multiple cognitive processes are involved in formulating responses to survey questions. This study also illustrates how the design and administration of the questionnaire influenced the response process and sometimes led respondents to struggle to formulate responses. Finally, this study suggests that men and women engaged in similar reporting processes, although stereotypical enactments of masculinity and femininity appear to have influenced the reporting of the symptom of phlegm. The findings of my study may help inform potentially beneficial revisions to the design and administration of the ATSQ, as well as the need to further investigate methods of analysis that take into account potential gender differences in the reporting of the symptom of phlegm. As rates of obstructive lung disease continue to increase (especially among women), effective measurement tools will help ensure the quality of the data we use to construct estimates of symptom prevalence for both men and women, which ultimately may help us to better understand the evolution of this emerging problem at the population level.

## BIBLIOGRAPHY

1. *Respiratory Disease in Canada*. 2001, Health Canada: Ottawa.
2. *Persons with asthma by age and sex*, S. Canada, Editor. 2001, Statistics Canada.
3. Kauffmann, F., and M. Becklake, *Sex and Gender*. European Respiratory Monograph, 2000. 5(15): p. 288-304.
4. Verbrugge, L.M., *Gender and health: an update on hypotheses and evidence*. Journal of Health & Social Behavior, 1985. 26(3): p. 156-82.
5. Ridgeway, C.L. and S.J. Correll, *Unpacking the gender system - A theoretical perspective on gender beliefs and social relations*. Gender & Society, 2004. 18(4): p. 510-31.
6. Annandale, E., and K. Hunt, *Gender inequalities in health: research at the crossroads*, in *Gender inequalities in health*, E. Annandale, and K. Hunt, Editor. 2000, Open University Press: Buckingham.
7. Ferris, B.G., *Epidemiology Standardization Project*. 1978.
8. Doyal, L., *Sex and gender: the challenges for epidemiologists*. International Journal of Health Services, 2003. 33(3): p. 569-79.
9. Krzyzanowski, M., and M. D. Lebowitz, *Changes in Chronic Respiratory Symptoms in Two Populations of Adults Studied Longitudinally over 13 Years*. European Respiratory Journal, 1992. 5: p. 12-20.
10. Lindstrom, M., J. Kotaniemi, E. Jonsson, and B. Lundback, *Smoking, Respiratory Symptoms, and Diseases. A Comparative Study between Northern Sweden and Northern Finland: Report from the FinEsS Study*. Chest, 2001. 119: p. 852-61.
11. Eagan, T.M., et al., *Incidence of asthma and respiratory symptoms by sex, age and smoking in a community study*. European Respiratory Journal, 2002. 19(4): p. 599-605.
12. Becklake, M.R., and F. Kauffmann, *Gender Differences in Airway Behaviour over the Human Life Span*. Thorax, 1999. 54: p. 1119-1138.
13. Annandale, E., and K. Hunt, *Masculinity, femininity and sex: an exploration to their relative contribution to explaining gender differences in health*. Sociology of Health and Illness, 1990. 12(1): p. 24-46.
14. Kim, J.S. and A.N. Nafziger, *Is it sex or is it gender?* Clin Pharmacol Ther, 2000. 68(1): p. 1-3.
15. Krieger, N., *Genders, sexes, and health: what are the connections-- and why does it matter?* International Epidemiological Association, 2003. 32: p. 652-7.
16. Moynihan, C., *Theories in health care and research: Theories of masculinity*. British Medical Journal, 1998. 317: p. 1072-5.
17. Oakley, A., *Sex, Gender and Society*. 1972, Melbourne: Temple Smith.
18. Boezen, H.M., D.F. Jansen, and D.S. Postma, *Sex and gender differences in lung development and their clinical significance*. Clin Chest Med, 2004. 25(2): p. 237-45.
19. MacIntyre, S., *Gender Differences in the Perceptions of Common Cold Symptoms*. Social Science and Medicine, 1993. 36(1): p. 15-20.

20. Popay, J., M. Bartley and C. Owen, *Gender Inequalities in Health: Social Position, Affective Disorders and Minor Physical Morbidity*. Social Science & Medicine, 1993. 36(1): p. 21-32.
21. Walters, V., P. McDonough, and L. Strohschein, *The influence of work, household structure, and social, personal and material resources on gender differences in health: an analysis of the 1994 Canadian National Population Health Survey*. Social Science & Medicine, 2002. 54(5): p. 677-92.
22. Courtenay, W.H., *Constructions of masculinity and their influence on men's well-being: A theory of gender and health*. Social science & medicine, 2000. 50(10): p. 1385.
23. Nathanson, C.A., *Illness and the feminine role: a theoretical review*. Social Science & Medicine, 1975. 9(2): p. 57-62.
24. Ballantyne, P.J., *The social determinants of health: a contribution to the analysis of gender differences in health and illness*. Scandinavian Journal of Public Health, 1999. 27(4): p. 290-5.
25. Kauffmann, F., and M. Becklake, *Maladies Respiratoires Obstructives: Un Paradigme de la Complexite des Differences de Sante entre Femmes et Hommes*, in *La Sante des Femmes*. 1996. p. 209-33.
26. Cioffi, D., *Beyond attentional strategies: a cognitive perceptual model of somatic interpretation*. Psychological Bulletin, 1991. 109: p. 25-41.
27. Leventhal, H., *Symptom reporting: a focus on process*, in *Illness behavior: a multidisciplinary model*, S. McHugh and T.M. Vallis, Editors. 1986, Plenum: New York.
28. Pennebaker, J.W., *The psychology of physical symptoms*. 1982, New York: Springer.
29. Teel, C., P. Meek, A. McNamara, L. Watson, and S. Lareau, *Perspective unifying symptom interpretation*. Journal of Nursing Scholarship, 1997. 29(2): p. 175-82.
30. Gijsbers Van Wijk, C.M.T., and Annemarie M. Kolk, *Sex Differences in Physical Symptoms: the Contribution of Symptom Perception Theory*. Social Science and Medicine, 1997. 45(2): p. 231-246.
31. Moller-Leimkuhler, A.M., *Barriers to Help-Seeking by Men: a Review of Sociocultural and Clinical Literature with Particular Reference to Depression*. Journal Of Affective Disorders, 2002. 71: p. 1-9.
32. Feldman, J.M., *Constructive processes as a source of context effects in survey research: explorations in self-generated validity*, in *Context Effects in Social and Psychological Research*, N. Schwarz, and S. Sudman, Editor. 1992, Springer-Verlag: New York.
33. Groves, R.M., F. J. Fowler, M. P. Couper, J. M. Lepkowski, E. Singer, and R. Tourangeau, *Survey Methodology*. 2004, Hoboken, New Jersey: Wiley.
34. Houtkoop-Steenstra, H., *Interaction and the standardized interview: the living questionnaire*. 2000, Cambridge: University Press.
35. Knauper, B., *Filter questions and question interpretation: presuppositions at work*. Public Opinion Quarterly, 1998. 62: p. 70-8.
36. Knauper, B., and P. Turner, *Measuring health: improving the validity of health assessments*. Quality of Life Research, 2003. 12(Suppl. 1): p. 81-9.

37. Schwarz, N., *Self-reports: how the questions shape the answers*. American Psychologist, 1999. 54(2): p. 93-105.
38. Sirken, M.G., D. Herrmann, S. Schechter, N. Schwarz, J. Tanur, and R. Tourangeau, ed. *Cognition and survey research*. 1999, John Wiley & Sons: New York.
39. Sudman, S., N. M. Bradburn, and N. Schwarz, *Thinking about answers: the application of cognitive processes to survey methodology*. 1996, San Francisco: Jossey-Bass.
40. Tanur, J.M., *Questions about questions: inquiries into the cognitive bases of surveys*. 1992, New York: Russell Sage.
41. Streiner, D., and G. Norman, ed. *Health measurement scales. A practical guide to their development and use*. 2nd ed. 1995, Oxford University Press: Oxford.
42. Mallinson, S., *Listening to respondents: a qualitative assessment of the Short-Form 36 Health Status Questionnaire*. Social Science & Medicine, 2002. 54: p. 11-21.
43. Schober, M.F., *Making sense of questions: an interactional approach*, in *Cognition and survey research*, M.G. Sirken, D. Herrmann, S. Schechter, N. Schwarz, J. Tanur, and R. Tourangeau, Editor. 1999, John Wiley & Sons: New York.
44. Schwarz, N., and S. Sudman, ed. *Context Effects in Social and Psychological Research*. 1992, Springer-Verlag: New York.
45. Davis, M.A., *Sex differences in reporting osteoarthritic symptoms: a sociomedical approach*. Journal of Health & Social Behavior, 1981. 22(3): p. 298-310.
46. Heitkemper, M., et al., *Impact of sex and gender on irritable bowel syndrome*. Biol Res Nurs, 2003. 5(1): p. 56-65.
47. Bogner, H.R. and J.J. Gallo, *Are higher rates of depression in women accounted for by differential symptom reporting?* Soc Psychiatry Psychiatr Epidemiol, 2004. 39(2): p. 126-32.
48. Mechanic, D., *Sex, Illness, Illness Behavior and the Use of Health Services*. Social Science & Medicine, 1978. 12B: p. 207-14.
49. Verbrugge, L.M., *The twain meet: empirical explanations of sex differences in health and mortality*. Journal of Health and Social Behavior, 1989. 30: p. 282-304.
50. Chen, W., S. L. Woods, and K. A. Puntillo, *Gender differences in symptoms associated with acute myocardial infarction: a review of the research*. Heart and Lung, 2005. 34: p. 240-7.
51. DeVon, H.A., and J. J. Zerwic, *Symptoms of acute coronary syndromes: are there gender differences? A review of the literature*. Heart and Lung, 2002. 31: p. 235-45.
52. Macintyre, S., K. Hunt, and H. Sweeting, *Gender differences in health: are things really as simple as they seem?* Social Science & Medicine, 1996. 42(4): p. 617-24.



53. Bekker, M.H.J., *Investigating gender within health research is more than sex disaggregation of data: a multi-facet gender and health model*. Psychology, Health and Medicine, 2003. 8(2): p. 231-43.
54. Kaplan, M., and G. Marks, *Appraisal of health risks: the roles of masculinity, femininity and sex*. Sociology of Health and Illness, 1995. 17: p. 206-21.
55. Robinson, M.E., et al., *Gender role expectations of pain: relationship to sex differences in pain*. Journal of Pain, 2001. 2(5): p. 251-7.
56. Denton, M., S. Prus, and V. Walters, *Gender differences in health: a Canadian study of the psychosocial, structural and behavioural determinants of health*. Social Science & Medicine, 2004. 58: p. 2585-2600.
57. Emslie, C., K. Hunt, and S. Macintyre, *Problematizing gender, work, and health: the relationship between gender, occupational grade, working conditions, and minor morbidity in full-time bank employees*. Social Science & Medicine, 1999. 48: p. 33-48.
58. Gijsbers van Wijk, C.M.T., H. Huisman, and A. M. Kolk, *Gender Differences in Physical Symptoms and Illness Behaviour: a Health Diary Study*. Social Science and Medicine, 1999. 49: p. 1061-1074.
59. Zeytinoglu, I.U., M. B. Seaton, W. Lillevik, and J. Moruz, *Working in the margins: women's experiences of stress and occupational health problems in part-time and casual retail jobs*. Women and Health, 2005. 41(1): p. 87-107.
60. Emslie, C., K. Hunt, and S. Macintyre, *Gender differences in minor morbidity among full time employees of a British university*. J Epidemiol Community Health, 1999. 53(8): p. 465-75.
61. Hibbard, J.H. and C.R. Pope, *Gender roles, illness orientation and use of medical services*. Social Science & Medicine, 1983. 17(3): p. 129-37.
62. Klonoff, E.A. and H. Landrine, *Sex roles, occupational roles, and symptom-reporting: a test of competing hypotheses on sex differences*. J Behav Med, 1992. 15(4): p. 355-64.
63. Nykvist, K., A. Kjellberg, and C. Bildt, *Causal explanations for common somatic symptoms among women and men*. International Journal of Behavioral Medicine, 2002. 9(3): p. 286-300.
64. Barsky, A.J., H.M. Peekna, and J.F. Borus, *Somatic symptom reporting in women and men*. J Gen Intern Med, 2001. 16(4): p. 266-75.
65. Koutantji, M., S. Pearce, and D. Oakley, *The relationship between Gender and Family History of Pain with Current Pain Experience and Awareness of Pain in Others*. Pain, 1998. 77: p. 25-31.
66. Wise, E.A., D. Price, C. Myers, M. Heft, and M. Robinson, *Gender Role Expectations of Pain: Relationship to Experimental Pain Perception*. Pain, 2002. 96: p. 335-42.
67. Saltonstall, R., *Healthy Bodies, Social Bodies: Men's and Women's Concepts and Practices of Health in Everyday Life*. Social Science & Medicine, 1993. 36(1): p. 7-14.
68. Gove, W.R., and M. Hughes, *Possible causes of the apparent sex differences in physical health: an empirical investigation*. American Sociological Review, 1979. 44(1): p. 123-46.

69. Langhammer, A., et al., *Cigarette smoking gives more respiratory symptoms among women than among men. The N rd-Trondelag Health Study (HUNT).* Journal of Epidemiology & Community Health, 2000. 54(12): p. 917-22.
70. Lindberg, A., A-C. Jonsson, E. Ronmark, R. Lundgren, L-G. Larsson, and B. Lundback, *Ten-year cumulative incidence of COPD and risk factors for incident disease in a symptomatic cohort.* Chest, 2005. 127: p. 1544-52.
71. Meren, M., L. Jannus-Pruljan, H.-M. Loit, J. Polluste, E. Jonsson, J Kiviloog and B. Lundback., *Asthma, Chronic Bronchitis and Respiratory Symptoms among Adults in Estonia According to a Postal Questionnaire.* Respir Med, 2001. 95: p. 954-64.
72. Sherman, C., X. Xu, F. Speizer, B. Ferris, S. Weiss and D. Dockery., *Longitudinal Lung function Decline in Subjects with Respiratory Symptoms.* Am Rev Respir Dis, 1992. 146: p. 855-59.
73. Viegi, G., M. Pedreschi, S. Baldacci, L. Chiaffi, F. Pistelli, P Modena, M. Vellutini, R. Di Pede, and L. Carrozzi, *Prevalence Rates of Respiratory Symptoms and Diseases in General Population Samples of North and Central Italy.* The International Journal of Tuberculosis and Lung Disease, 1999. 3(11): p. 1034-42.
74. Viegi, G., et al., *Prevalence of airways obstruction in a general population: European Respiratory Society vs American Thoracic Society definition.* Chest, 2000. 117(5 Suppl 2): p. 339S-45S.
75. Kanner, R.E., et al., *Gender difference in airway hyperresponsiveness in smokers with mild COPD. The Lung Health Study.* American Journal of Respiratory & Critical Care Medicine, 1994. 150(4): p. 956-61.
76. Vestbo, J., and P. Lange, *Can GOLD stage 0 provide information of prognostic value in chronic obstructive pulmonary disease?* American Journal of Respiratory & Critical Care Medicine, 2002. 166: p. 329-32.
77. Cerveri, I., et al., *Chronic cough and phlegm in young adults.* European Respiratory Journal, 2003. 22(3): p. 413-7.
78. Larsson, M.L., et al., *Passive smoking and respiratory symptoms in the FinEsS Study.[see comment].* European Respiratory Journal, 2003. 21(4): p. 672-6.
79. French, C.T., K.E. Fletcher, and R.S. Irwin, *Gender differences in health-related quality of life in patients complaining of chronic cough.* Chest, 2004. 125(2): p. 482-8.
80. French, C.T., K.E. Fletcher, and R.S. Irwin, *A comparison of gender differences in health-related quality of life in acute and chronic coughers.* Chest, 2005. 127(6): p. 1991-8.
81. Cydulka, R.K., et al., *Differences between men and women in reporting of symptoms during an asthma exacerbation.* Ann Emerg Med, 2001. 38(2): p. 123-8.
82. Weiner, P., R. Magadle, F. Massarwa, M. Beckerman and N. Berar-Yanay, *Influence of gender and inspiratory muscle training on the perceptions of dyspnea in patients with asthma.* Chest, 2002. 122: p. 197-201.
83. Adams, M.L., *'Death to the Prancing Prince': Effeminacy, Sport Discourses and the Salvation of Men's Dancing.* Body & Society, 2005. 11(4): p. 63.

84. Reeser, J.C., *Gender identity and sport: is the playing field level?* British journal of sports medicine, 2005. 39(10): p. 695.
85. Banzett, R., J. Dempsey, D. O'Donnell, and M. Wamboldt, *Symptom Perception and Respiratory Sensation in Asthma: NHLBI Workshop Summary*. American Journal of Respiratory & Critical Care Medicine, 2000. 162: p. 1178-82.
86. De Peuter, S., et al., *Dyspnea: the role of psychological processes*. Clinical Psychology Review., 2004. 24(5): p. 557-81.
87. Elliott, M.W., L. Adams, A. Cockcroft, K. Macrae, K. Murphy, and A. Guz, *The Language of Breathlessness: Use of Verbal Descriptors by Patients with Cardiopulmonary Disease*. American Review of Respiratory Disease, 1991. 144: p. 826-32.
88. Martinez-Moragon, E., et al., *Determinants of dyspnea in patients with different grades of stable asthma*. Journal of Asthma. 40(4): p. 375-82.
89. Knuiman, M.W., et al., *Lung function, respiratory symptoms, and mortality: Results from the Busselton Health Study*. Annals Of Epidemiology, 1999. 9(5): p. 297-306.
90. Silverman, E.K., et al., *Gender-related differences in severe, early-onset chronic obstructive pulmonary disease*. Am J Respir Crit Care Med, 2000. 162(6): p. 2152-8.
91. Anto, J.M., et al., *Epidemiology of chronic obstructive pulmonary disease*. Eur Respir J, 2001. 17(5): p. 982-94.
92. Camp, P.G., H. Dimich-Ward, and S.M. Kennedy, *Women and occupational lung disease: sex differences and gender influences on research and disease outcomes*. Clin Chest Med, 2004. 25(2): p. 269-79.
93. Chapman, K.R., Donald P. Tashkin, and David J. Pye, *Gender Bias in the Diagnosis of COPD*. Chest, 2001. 119: p. 1691-1695.
94. Charmaz, K., *Grounded Theory: Objectivist and Constructivist Methods*, in *The handbook of qualitative research*, N.K. Denzin, and Y. S. Lincoln, Editor. 2000, Sage Publications: Thousand Oaks.
95. Kennedy, S., H. Dimich-Ward, S. Vedal, S. Kwan, and B. Karlen, *Abestos monitoring program for BC Ferry Corporation employees: a report of findings*. 2000, University of British Columbia: Vancouver.
96. Adamson, J., Rachael Gooberman-Hill, Gillian Woolhead, and Jenny Donovan, *'Questerviews': Using Questionnaires in Qualitative Interviews as a Method of Integrating Qualitative and Quantitative Health Services Research*. Journal of Health Services Research Policy, 2004. 9(3): p. 139-45.
97. Strauss, A., and J. Corbin, *Basics of Qualitative Research: techniques and procedures for developing grounded theory*. 2nd edition ed. 1998, Thousand Oaks: Sage.
98. Hall, W., and P. Callery, *Enhancing the rigor of grounded theory: incorporating reflexivity and relationality*. Qualitative Health Research, 2001. 11(2): p. 257-72.
99. Poirier, S., and L. Ayres, *Endings, Secrets, and Silences: Overreading in Narrative Inquiry*. Research in Nursing & Health, 1997. 20: p. 551-57.

100. Leidy, N.K., J. K. Schmier, M. K. C. Jones, J. Lloyd, and K. Rocchiccioli, *Evaluating symptoms in chronic obstructive pulmonary disease: validation of the Breathlessness, Cough and Sputum Scale*. Respiratory Medicine, 2003. 97(Suppl A): p. S59-S70.
101. Jakeways, N., T. McKeever, S. A. Lewis, S. T. Weiss, and J. Britton, *Relationship between FEV1 reduction and respiratory symptoms in the general population*. European Respiratory Journal, 2003. 21: p. 658-663.
102. Borawski, E., J. Kinney, and E. Kahana, *The Meaning of Older Adults' Health Appraisals: congruence with health status and determinant of mortality*. Journal of Gerontology: Social Sciences, 1996. 51B(3): p. S157-70.

## **APPENDIX A**

### Characteristics of the Sample

Alias	Sex	Age	Job	Smoking	Diagnosis	Q Version	Previous Sx	Current Sx
Dean	M	47	Shipyard	Ex	Hay fever, Bronchitis	Original	No	Cough day/night
Adam	M	46	Shipyard	Never	None	Original	No	Morning cough
Peter	M	45	Shipyard	Never	Bronchitis	Original	No	None
Barry	M	32	Shipyard	Never	None	Original	N/A	Cough, Phlegm, Episodes, Wheeze (with cold)
James	M	53	Shipyard	Current	Hay Fever	Original	Phlegm, Wheeze	Phlegm
Frank	M	52	Shipyard	Never	Asthma, Hay Fever, Bronchitis	Revised	Wheeze, No-Yes Dyspnea	Episodes, Wheeze
Evelyn	F	59	Cleaning	Ex	None	Original	Wheeze	Dyspnea
Gary	M	67	Retired	Ex-never	Bronchitis	Original	No-yes phlegm	Cough, Phlegm, Episodes, Wheeze
Alex	M	46	Engineer	Ex	None	Original	N/A	None
Tyler	M	51	Shipyard	Never	None	Revised	No	None
Lionel	M	73	Retired	Never	None	Revised	No	None
Ben	M	60	Retired	Ex	Asthma	Original	Phlegm, Wheeze and Dyspnea	Cough, Phlegm, Episodes, Wheeze, Dyspnea
Doris	F	66	Retired	Ex	Bronchitis	Revised	None	Dyspnea
Bertha	F	59	Admin	Ex	Asthma, Bronchitis, Pneumonia	Original	Yes-no wheeze, Dyspnea	Cough, Phlegm, Episodes, Wheeze, Dyspnea
Anne	F	61	Shorehand	Never	Bronchitis	Original	Dyspnea	Morning Phlegm, Dyspnea
Dorothy	F	62	Catering	Ex	Bronchitis	Revised	N/A	None
Nancy	F	42	Shipyard	Never	None	Original	None	None
Carol	F	46	Catering	Current	None	Revised	Yes-No cough, Yes-No Wheeze, Yes-No Dyspnea	Cough, Phlegm, Wheeze, Dyspnea

Ginny	F	49	Catering	Ex	Asthma	Revised	No-Yes Cough, No-Yes Dyspnea, and No-Yes Wheeze	Wheeze, Dyspnea
Heather	F	50	Tower Control	Never	None	Revised	None	None
Francine	F	56	Retired	Current	Bronchitis	Revised	Yes-No Dyspnea	None
Kevin	M	50	Shipyard	Never	None	Original	n/a	Phlegm
Scott	M	57	Retired	Never	None	Revised	No-Yes Dyspnea	Dyspnea
Darryl	M	43	Catering	Current	None	Original	n/a	Occasional wheeze
Beth	F	45	Admin	Never	None	Original	Phlegm	Phlegm
Vince	M	61	Retired	Never	None	Original	No-Yes Phlegm and Dyspnea	Dyspnea
Brenda	F	87	Retired	Never	None	Revised	Phlegm, wheeze, Dyspnea	Phlegm (morning only), Dyspnea
Robert	M	85	Retired	Never	None	Revised	Phlegm, Wheeze	Phlegm, Wheeze
Lindsay	F	56	Admin	Ex	Bronchitis, Pneumonia and hay fever	Revised	Yes-No Wheeze, No-Yes Dyspnea	Dyspnea
Noah	M	73	Retired	Ex	Congestive heart failure	Revised	Dyspnea	Dyspnea
Victoria	F	62	Admin	Ex	None	Revised	Wheeze, Dyspnea	Wheeze
Isabelle	F	53	Retired	Ex	Bronchitis	Original	No Sx	None
Roger	M	71	Retired	Ex	Heart trouble	Revised	Cough, Dyspnea	Wheeze, Dyspnea
Oliver	M	57	Engineer	Never	Hayfever	Revised	Yes-No Phlegm, Yes-No Wheeze	None
John	M	70	Retired	Ex	Pneumonia	Original	No-Yes Cough, No-Yes Phlegm, No-Yes Wheeze	Morning cough, phlegm
Olivia	F	64	Catering	Current	None	Original	Cough, Wheeze	Wheeze (with colds)
Wendy	F	47	Other	Ex	Bronchitis	Original	Yes to No Dyspnea	None
Patty	F	55	Catering	Current	Asthma, Hay Fever	Revised	Wheeze, Dyspnea	Wheeze, Dyspnea
Sylvia	F	48	Admin	Never	Bronchitis	Revised	None	None
Jessica	F	71	Retired	Ex	None	Original	n/a	None

## **APPENDIX B**



# Original American Thoracic Society Questionnaire: Cough, Phlegm, Episodes of Cough with Phlegm, Wheeze, and Dyspnea

## Part 2. Respiratory Symptoms

The following questions are about respiratory or chest symptoms. If you are in doubt whether the answer is yes or no, please answer no.

### 2.1 COUGH

A. Do you usually have a cough? (count cough with first smoke or first going out of doors. Exclude clearing throat.) 1. Yes ☐ 0. No ☐ [ ] 15

IF YES TO 'A', ask:

B. Do you usually cough as much as 4 times a day, 4 or more days out of the week? 1. Yes ☐ 0. No ☐ [ ] 16

IF NO TO 'A', ask:

C. Do you usually cough at all on getting up or first thing in the morning? 1. Yes ☐ 0. No ☐ [ ] 17

D. Do you usually cough at all during the rest of the day or night? 1. Yes ☐ 0. No ☐ [ ] 18

IF YES TO ANY OF ABOVE, ask:

E. Do you usually cough like this most days for 3 consecutive months or more during the year? 1. Yes ☐ 0. No ☐ [ ] 19

F. For how many years have you had this cough? number of years [ ] [ ] 20 21

G. Does the cough improve:  
on days off? 1. Yes ☐ 0. No ☐ [ ] 22  
on long holidays? 1. Yes ☐ 0. No ☐ [ ] 23

H. Is there anything or situation which makes your cough worse? 1. Yes ☐ 0. No ☐ [ ] 24  
[ ] [ ] 25 26

Specify:

## 2.2 PHLEGM

1A. Do you usually bring up phlegm from your chest? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 27

(count phlegm with first smoke or first going out of doors.  
Count swallowed phlegm. Exclude phlegm from the nose.)

IF YES TO 'A', ask:

A. Do you usually bring up phlegm like this as much as  
twice a day, 4 or more days out of the week? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 28

IF NO TO 'A', ask:

C. Do you usually bring up phlegm at all on getting up or  
first thing in the morning? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 29

D. Do you usually bring up phlegm at all during the rest of  
the day or night? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 30

IF YES TO ANY OF ABOVE, ask:

E. Do you usually bring up phlegm like this most days for 3  
consecutive months or more during the year? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 31

F. For how many years have you had trouble with phlegm?  
number of years [ ] [ ]  
32 33

G. Does the phlegm improve:  
on days off? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 34  
on long holidays? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 35

H. Is there anything or situation which makes you bring up  
phlegm? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 36  
[ ] [ ]  
37 38

Specify: \_\_\_\_\_

2. A. In the past 12 months, have you had periods or episodes of  
cough with phlegm that lasted 1 week or more? (If you usually  
have cough and phlegm, please count only periods or episodes of  
increased cough and phlegm.) 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 39

B. About how many such episodes have you had in the past  
12 months? number of episodes [ ] [ ]  
40 41

C. For how many years have you had at least 1 such episode?  
number of years [ ] [ ]  
42 43

## 2.3 WHEEZING

Does your chest ever sound wheezy or whistling.

- A. When you have a cold? 1. Yes ☐ 0. No ☐ [ ] 44
- B. Occasionally apart from colds? 1. Yes ☐ 0. No ☐ [ ] 45
- C. Most days and nights? 1. Yes ☐ 0. No ☐ [ ] 46

IF YES TO 'B' or 'C', ask:

- D. Is the wheeze associated with chest tightness or difficulty breathing? 1. Yes ☐ 0. No ☐ [ ] 47
- E. For how many years has this been present?  number of years [ ] 48 49
- F. When does the wheeze occur MOST frequently? (choose one)
- |                                        |                                        |        |
|----------------------------------------|----------------------------------------|--------|
| 1. at work <input type="text"/>        | 2. on return home <input type="text"/> | [ ] 50 |
| 3. during sleep <input type="text"/>   | 4. no difference <input type="text"/>  |        |
| 5. upon waking up <input type="text"/> |                                        |        |
- G. Does the wheeze improve:
- |                                            |                                                                |        |
|--------------------------------------------|----------------------------------------------------------------|--------|
| on days off? <input type="checkbox"/>      | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 51 |
| on long holidays? <input type="checkbox"/> | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 52 |
- H. Is there anything or situation which makes you wheeze? 1. Yes ☐ 0. No ☐ [ ] 53
- \* if yes:
- |                                        |                                                                |           |
|----------------------------------------|----------------------------------------------------------------|-----------|
| Exercise <input type="checkbox"/>      | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 54    |
| Cold air <input type="checkbox"/>      | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 55    |
| Tobacco smoke <input type="checkbox"/> | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 56    |
| Strong odour <input type="checkbox"/>  | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 57    |
| Fumes or dust <input type="checkbox"/> | 1. Yes <input type="checkbox"/> 0. No <input type="checkbox"/> | [ ] 58    |
| Other, specify: <input type="text"/>   |                                                                | [ ] 59 60 |
- I. Is the wheezing worse at any particular time of the year? 1. Yes ☐ 0. No ☐ [ ] 61
- \* if yes, when:  [ ] 62 63

## 2.5 BREATHLESSNESS

Row # [

INTERVIEWER - Check here if person is unable to walk due to conditions other than shortness of breath. 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 3

A. Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 4

IF YES TO 'A', ask:

B. Do you have to walk slower than people of your own age, on the level, because of breathlessness? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 5

C. Do you ever have to stop for breath when walking at your own pace on level ground? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 6

D. Do you ever have to stop for breath after walking about 100 yards (or a few minutes) on the level? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 7

E. For how many years have you had shortness of breath? \_\_\_\_\_ number of years [ ] 8 9

F. Does it improve:  
on days off? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 10  
on long holidays? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 11

## Revised American Thoracic Society Questionnaire: Cough, Phlegm, Episodes of Cough with Phlegm, Wheeze, and Dyspnea

### Part 2. Respiratory Symptoms

The following questions are about respiratory or chest symptoms. If you are in doubt whether the answer is yes or no, answer no.

#### 2.1 COUGH

1. A. Do you usually have a cough? (count cough with first smoke or first going out of doors. Exclude clearing throat.) 1. Yes ☐ 0. No ☐ [ ] 24

IF YES TO 'A', ask:

1. B. Do you usually cough as much as 4 times a day, 4 or more days out of the week? 1. Yes ☐ 0. No ☐ [ ] 25

IF NO TO 'A', ask:

1. C. Do you usually cough at all on getting up or first thing in the morning? 1. Yes ☐ 0. No ☐ [ ] 26

1. D. Do you usually cough at all during the rest of the day or night? 1. Yes ☐ 0. No ☐ [ ] 27

IF YES TO ANY OF ABOVE, ask:

1. E. Do you usually cough like this most days for 3 consecutive months or more during the year? 1. Yes ☐ 0. No ☐ [ ] 28

1. F. For how many years have you had this cough? [ ] [ ] [ ]  
number of years 29-30

1. G. Does the cough improve: on days off? 1. Yes ☐ 0. No ☐ [ ] 31

on long holidays? 1. Yes ☐ 0. No ☐ [ ] 32

H. Is there anything or situation which makes your cough worse? 1. Yes ☐ 0. No ☐ [ ] 33

Specify: [ ] [ ] 34-35

2. A. In the last 12 months, have you been awakened from sleep by coughing? 1. Yes ☐ 0. No ☐ [ ] 36

IF YES TO 'A', ask:

2.B. In the last 12 months, how often have you been awakened by coughing?

[ ] 37

1. Most Days or Nights \_\_\_\_\_
2. A few days or nights a week \_\_\_\_\_
3. A few days or nights a month \_\_\_\_\_
4. A few days or nights a year, or less \_\_\_\_\_

## 2.2 PHLEGM

1.A. Do you usually bring up phlegm from your chest?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 38

(count phlegm with first smoke or first going out of doors.  
Count swallowed phlegm. Exclude phlegm from the nose.)

IF YES TO 'A', ask:

1.B. Do you usually bring up phlegm like this as much as twice a day, 4 or more days out of the week?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 39

IF NO TO 'A', ask:

1.C. Do you usually bring up phlegm at all on getting up or first thing in the morning?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 40

1.D. Do you usually bring up phlegm at all during the rest of the day or night?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 41

IF YES TO ANY OF ABOVE, ask:

1.E. Do you usually bring up phlegm like this most days for 3 consecutive months or more during the year?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 42

1.F. For how many years have you had trouble with phlegm?

number of years

[ ] 43  
43 - 44

1.G. Does the phlegm improve:

on days off?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 45

on long holidays?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 46

H. Is there any thing or situation which makes you bring up

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 47

phlegm?

[ ] 48

48 - 49

Specify: \_\_\_\_\_

2.A. In the past 12 months, have you had periods or episodes of cough with phlegm that lasted 1 week or more? (If you usually have cough and phlegm, please count only periods or episodes of increased cough and phlegm.) 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 50

B. About how many such episodes have you had in the past 12 months? \_\_\_\_\_ number of episodes [ ] 51

C. For how many years have you had at least 1 such episode? \_\_\_\_\_ number of years [ ] 52

### 2.3 WHEEZING

1.A. Have you ever had wheezing or whistling in your chest? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 53

IF NO TO 'A', SKIP TO NEXT SECTION.

IF YES TO 'A', ask:

1.B-D. Did you have wheezing or whistling in your chest when you were...

1.B. Younger than 2 years old? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 54

1.C. 2 to 18 years old? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 55

1.D. Older than 18 years old? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 56

2.A. In the last 12 months, have you had wheezing or whistling in your chest at any time? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 57

IF NO TO 'A', SKIP TO QUESTION 3.

IF YES TO 'A', ask:

2.B. In the last 12 months, how often have you had this wheezing or whistling? [ ] 58

1. Most Days or Nights \_\_\_\_\_

2. A few days or nights a week \_\_\_\_\_

3. A few days or nights a month \_\_\_\_\_

4. A few days or nights a year, or less \_\_\_\_\_

2.C. In the last 12 months, have you had this wheezing or whistling in the chest when you had a cold? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 59

2.D. In the last 12 months, have you had this wheezing or whistling in the chest apart from colds? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 60

2.E. In the last 12 months have you had an attack of 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 61

wheezing or whistling in the chest that has made you feel short of breath?

2.F. In the last 12 months, has this wheezing or whistling improved:

On days off?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 62

On long holidays?

1. Yes \_\_\_\_ 0. No \_\_\_\_

[ ] 63

2.G. When does the wheeze occur MOST frequently? (choose one)

[ ] 64

1. at work

2. on return home

3. during sleep

4. no difference

5. upon waking up

3.A. In the last 12 months, have you been awakened from sleep by wheezing or whistling in your chest? 1. Yes \_\_\_\_ 2. No \_\_\_\_ [ ] 65

IF NO TO 'A', SKIP TO NEXT SECTION

IF YES TO 'A', ask:

3.B. In the last 12 months, how often have you been awakened by wheezing or whistling in your chest? [ ] 66

1. Most Days or Nights

2. A few days or nights a week

3. A few days or nights a month

4. A few days or nights a year, or less

## 2.5 BREATHLESSNESS

INTERVIEWER -- Check here if person is unable to walk due to conditions other than shortness of breath. 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 69

IF YES TO '1', SKIP TO NEXT SECTION

1.A. Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 70

IF NO TO 'A', SKIP TO NEXT SECTION

IF YES TO 'A', ask:

1.B. Do you have to walk slower than people of your age on level ground because of shortness of breath? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 71

1.C. Do you ever have to stop for breath when walking at your own pace on level ground? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 72

1.D. Do you ever have to stop for breath after walking about 100 yards (or a few minutes) on level ground? 1. Yes \_\_\_\_ 0. No \_\_\_\_ [ ] 73



1. E. Are you too short of breath to leave the house or short of breath on dressing or undressing? 1. Yes \_\_\_\_\_ 0. No \_\_\_\_\_ [ ] 74

1.F. Does it improve:

On days off?

1. Yes \_\_\_\_\_ 0. No \_\_\_\_\_ [ ] 75

On long holidays?

1. Yes \_\_\_\_\_ 0. No \_\_\_\_\_ [ ] 76

## **APPENDIX C**

## Semi-Structured Interview Guide

**PREFACE TO BEGINNING INTERVIEW:** You answered a series of questions about cough, phlegm, wheeze, breathlessness and sleep symptoms. Now I'd like to ask you some more in-depth questions about the way you understood those questions and how you formed your answers to those questions. What I'm looking for is a description of the reasons why you answered the questions the way that you did.

### **Cough**

- How did you decide on your answer to this question? How did you interpret or decide what this question was asking? How would you define what was meant by usually have a cough?
- Thinking back, is there a time where you would have answered this question differently? Can you tell me what changed to lead you to change your response?
- *In general*, how far back in your memory did you go when deciding how to answer these questions on cough?
- *Some people experience "coughing spells" (which go on and on) and others report milder, brief coughs. Some people cough all throughout the day, others just cough when they have a cold or are bothered by something in the air and still others only cough in the morning or at night.* Tell me about the kinds of coughs that you experience and how coughing affects your daily life. How do people react to your coughing? Has anyone commented on your coughing?
- What did you think or feel when you were around someone who coughed a lot?
- Do you ever resist the urge to cough? What makes it acceptable to allow yourself to cough in some situations and not in others?
- Do you think that it is more or less appropriate for a man or a woman to answer, "Yes, I usually have a cough"?

### **Phlegm**

- How did you decide on your answer to this question? How did you interpret or decide what this question was asking? How would you define what was meant by usually bring up phlegm from your chest?
- *In general*, how far back in your memory did you go when deciding how to answer these questions on cough? Thinking back, is there a time where you would have answered "no" to this question? Can you tell me what changed to lead you to change your response?
- *For many people, coughing up phlegm is relatively easy. For others, it's very difficult to bring it up out of their chests.* How does bringing up phlegm affect your daily life? Are there situations where you experience phlegm but don't cough it up? Situations where you do cough it up, but do not or cannot spit it out (e.g., you are in a public place)? Situations where you are more likely to cough it up? Spit it out? Swallow it?
- What did you think or feel when you were around someone who brought up phlegm from their chest? Spat it out?
- Do you think that it is more or less appropriate for a man or a woman to answer, "Yes, I usually bring up phlegm from my chest"?

### **Episodes of Cough with Phlegm**

- What led you to answer this question the way that you did?
- In your own words, how is this question about episodes of cough with phlegm different from the previous question of cough on its own and phlegm on its own?
- In your experience, what does it mean to experience an episode of cough with phlegm?

### **Wheezing or Whistling**

- How did you decide on your answer to this question? How did you interpret or decide what this question was asking? How would you define what was meant by a wheezing or whistling chest?

- *In general, how far back in your memory did you go when deciding how to answer this question on wheeze? Thinking back, is there a time where you would have answered “no” to this question? Can you tell me what changed to lead you to change your response?*
- *Some people experience wheezing or whistling in their chest because of colds while others experience this without having a cold. Some people experience such severe wheezing/whistling (sometimes lengthy in duration) that they feel short of breath, while others report more mild or brief wheezing/whistling. Still others report wheezing/whistling only at night. Tell me about your experiences of having a wheezing/whistling chest. How does this affect your daily life? How do people react to your wheeze or whistling chest?*
- *Some people find it easy to manage their symptoms of wheeze, while others struggle with this. How do you manage your symptoms?*
- *What do you think or feel when you are around someone who wheezes or has a whistling chest?*
- *Do you think that it is more or less appropriate for a man or a woman to answer, “Yes, I have or have had a wheezy/whistling chest”?*

#### **Shortness of Breath**

- *How did you decide on your answer to this question? How did you interpret or decide what this question was asking? How would you define what was meant by troubled by shortness of breath? How would you define hurrying on level ground or walking up a slight hill?*
- *In general, how far back in your memory did you go when deciding how to answer these questions on shortness of breath? Thinking back, is there a time where you would have answered this question differently? Can you tell me what changed to lead you to change your response?*
- *The questions that were asked of you regarding shortness of breath refer to walking activities and dressing or undressing. Are there other situations where you feel short of breath?*
- *People use many different words to describe the feeling of being short of breath. How would you describe your experiences of being short of breath? Why do you think you experience shortness of breath (e.g., is it stress, strenuous activity, health problem)?*
- *How does shortness of breath affect your day to day life activities and how does this make you feel about yourself – at work? At home? During recreation?*
- *How do others react to your shortness of breath? Has anyone ever commented on this? What did they say?*
- *What do you think or feel when you are around someone who is short of breath? Do you think that shortness of breath is a reflection of an individual’s level of fitness? Health?*
- *Do you think that it is more or less appropriate for a man or a woman to answer, “Yes, I experience shortness of breath”?*

## **APPENDIX D**

### Consent to Participate

Your participation in this research is entirely voluntary. You may withdraw from any part of this study at any time if you desire. Voluntary withdrawal from any part of the study will not affect your work, your participation in other parts of the study, or your continuing health care in any way.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature below indicates that you consent to participate in this study.

Subject # 78 - _____	
Subject Name: _____ (Please print)	
Signature _____	Date _____
Witness Name: _____ (Please print)	
Witness Signature _____	Date _____

In the absence of a witness for the above signature.

Designated Representative of Principal Investigator:	
Name: _____ (Please print)	
Signature _____	Date _____

## **APPENDIX E**